

WEST VIRGINIA  
FIVE YEAR NEEDS ASSESSMENT  
JULY 2005

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## **WEST VIRGINIA FIVE YEAR NEEDS ASSESSMENT**

### **I. Five Year Needs Assessment Process**

The Needs Assessment Process was coordinated within the West Virginia Office of Maternal, Child and Family Health by the Division of Research, Evaluation and Planning and included assistance from the Office Director, Division Directors of: Perinatal and Women's Health, Infant, Child and Adolescent Health, Children with Special Health Care Needs and Finance. Surveys were sent out within the perinatal health program called Right From The Start (RFTS), CSHCN, Oral Health Program and the Adolescent Pregnancy Prevention Initiative. Statewide forums were held in public libraries at six (6) sites across the State in strategic locations for the past five years and Medical/Program Advisory Committees for Newborn Screening, Birth Defects, CSHCN, Child and Adolescent Health, and Childhood Lead Poisoning have been involved in assessing the needs of the targeted program population. Data is used from multiple sources including WV's Health Statistics Center, the state's perinatal program (Right From The Start), Kids Count, WVU Birth Score Office (risk tool used to determine risk for post neonatal death and developmental delay in newborns), Social Security Administration, the YRBS, PRAMS, etc. Following is a brief description of efforts across the state that the Title V Program has either initiated or been involved with, and we have used the information to assist in developing the needs assessment. This is not an all inclusive list of efforts.

The Adolescent Pregnancy Prevention Initiative conducted anonymous surveys of students participating in classroom presentations in the 2003-2004 school year. The survey tool, provided by Advocates for Youth, assessed student opinions (grades 6-12) on school-based sexuality education. Highlights from 1,001 surveys are summarized on pages 45 and 46.

The Youth Risk Behavior Survey (YRBS) was developed by the Division of Adolescent and School Health, National Center for Chronic Disease Prevention, Centers for Disease Control and Prevention (CDC). In collaboration with the West Virginia Department of Education, the 2003 YRBS was designed to monitor priority health-risk behaviors that contribute to the leading causes of disease, death, and social problems among youth. Research indicates that these behaviors and the resulting health problems are largely preventable. The students who participated in the survey are representative of students in West Virginia. The results can be used to make inferences concerning the health risk behaviors of all West Virginia public high school students in grades 9 through 12.

In the Fall 2003, the first of the Adult and Children's Mental Health/Substance Abuse Key Stakeholder Team meetings took place. The purpose of the meetings was to produce a three-year plan to improve quality of and access to adult and children's

mental health and substance abuse services. Participants attended from state government, community mental health centers, practicing mental health providers, clients and families. The teams identified seven areas as key priority areas to be addressed for the Fiscal Year 2005 Block Grant and Bureau of Behavior Health and Health Facilities state plan. These areas are: Community Integration, Workforce Development, Transitioning Issues, Basic Needs, Intervention, Prevention, and Access to Services.

The West Virginia DHHR/Bureau for Public Health/Office of Maternal, Child and Family Health/Oral Health Program (OHP) has received frequent anecdotal reports of children with special health care needs (CSHCN) having problems obtaining dental care. A survey was developed jointly by the CSHCN Program and the Oral Health Program and was sent to the parents of all of the children enrolled in the WV CSHCN Program. It was learned that 72% of the CSHCN enrollees saw a dentist in the last year. Recommendations included: Oral Health Program survey dentists to determine their willingness to treat children with special needs; develop a directory for families to use when choosing a dentist; distribution of the directory to all CSHCN families and inclusion of the directory on the MCFH web site for families use; recruitment of dentists in underserved areas; and arrange training opportunities for general dentists on treating children with special needs.

A 2004-2005 Immunization Kindergarten School Survey was conducted through the cooperation of the Department of Education. On-site validation audits for immunizations were conducted in 60 schools across the state for kindergarten enterers and first grade students who transferred from out of state during the 2004-2005 school year. Audit results revealed: 1.63% (36 students) were missing at least one required immunization, 0.40% (9 students) had invalid doses which were counted, 0.27% (6 students) had no records for immunization, and a total of 2.31% (51 students) were non-compliant.

In the 2002-2003 school year, the West Virginia Department of Education's Office of Student Services and Health Promotion planned and implemented its first statewide assessment of health education. A team of health educators from across WV planned and implemented this assessment. Assessment items were taken from the State Collaborative on Assessment and Student Standards Health Education Assessment Project (SCASS-HEAP). Health education content areas and items were selected based on the extent to which they aligned with the WV Health Education Content Standards and Objectives (CSOs). All grades included items on the health education content areas of nutrition, physical activity, growth and development, alcohol and other drugs and tobacco. Grade 6 included items on injury prevention and 8<sup>th</sup> grade and high school versions included questions on mental health. Seven additional items, taken from the beginning of the Youth Risk Behavior Survey, were also used. These items asked for information on students' age, sex, grade, race and height and weight.

The West Virginia Birth to Three Transition Exit Survey was developed as a collaborative effort of between Part C/IDEA, West Virginia Department of Education, Head Start, and Child Care. The survey is designed to address monitoring priorities of the U.S. Department of Education and provide information for improvement of family and child outcomes. Survey questions ask about the outcome of the child/family's transition; whether Part C services helped the family to meet their child's developmental needs; promoted the child's participation in daily routines; and helped to promote the child's development across developmental domains.

For two years, the West Virginia Department of Health and Human Resources, West Virginia Birth to Three (WV BTT), providing early intervention to children with special needs, and the West Virginia Department of Education, Office of Special Education (OSE), administering special education programs for students ages 3-21, collaborated with representatives of other agencies and parents in a process to assess the effectiveness of services supported by the Individuals with Disabilities Education Act, Amendments of 1997 (IDEA 97). This Improvement Plan has been developed in response to the priorities identified through that IDEA Self-Assessment Process.

The West Virginia IDEA Self-Assessment Process report was submitted to the US Office of Special Education in October 2002. West Virginia responded to requests for further information from OSE in early January 2003. In anticipation of receiving a response to the report, the OSE and WV BTT scheduled a State Improvement Plan meeting January 28-30, 2003. At that time, Steering Committee convened to review the IDEA Self-Assessment report and make recommendations for priorities to be addressed in the state improvement plan. (See page 121 for recommendations).

In December of 2002, a Summit on Obesity was held at the Embassy Suites in Charleston, WV. Key stakeholders throughout the state were invited to attend this Summit in the hopes that partnerships could be developed to work on carrying out strategies to reduce the burden of obesity in West Virginia. The partnership panel included participants from West Virginia University Health Sciences, West Virginia Department of Education Office of Healthy Schools, the West Virginia Bureau for Public Health, the West Virginia State Medical Association, Partners in Corporate Health, Incorporated and the Institute Church of the Nazarene.

Following is the OMCFH State Five Year Needs Assessment for WV by MCH population groups, Capacity by Pyramid Levels, Challenges and Summary:

- A) Pregnant women, Women of childbearing age, and Infants
- B) Children and Adolescents
- C) Children with Special Health Care Needs
- D) Capacity by Pyramid Levels
- E) Challenges
- F) Summary

**A. State MCH Population Group:**

**Pregnant Women,  
Women of Childbearing Age,  
Mothers and Infants**



## **A. STATE MCH POPULATION GROUP: PREGNANT WOMEN, WOMEN OF CHILDBEARING AGE, MOTHERS AND INFANTS**

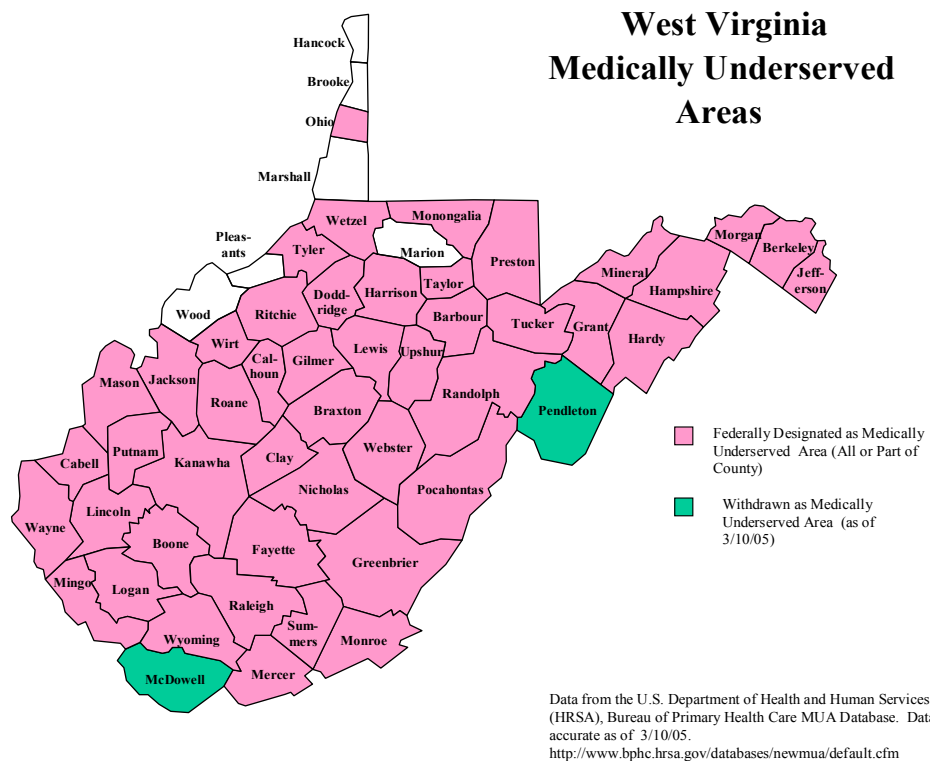
A broad assessment was completed in the areas listed below:

- **ACCESS TO HEALTH CARE**
- **PREMATURITY AND LOW BIRTH WEIGHT IN WEST VIRGINIA**
- **NEONATAL/POST-NEONATAL/INFANT DEATHS**
- **NEWBORN METABOLIC SCREENING**
- **SUDDEN INFANT DEATH SYNDROME (SIDS)**
- **BIRTH DEFECTS**
- **SUBSTANCE ABUSE, TOBACCO CESSATION, SMOKING DURING  
PREGNANCY AND SECOND HAND SMOKE EXPOSURE**
- **MENTAL HEALTH ISSUES**
- **DOMESTIC VIOLENCE**
- **PERINATAL (RFTS) INFRASTRUCTURE**
- **DATA COLLECTION AND ANALYSIS**
- **FAMILY PLANNING**
  - Unintended Pregnancy/Teen Pregnancy
  - Adolescent Pregnancy Prevention Initiative
  - Abstinence
  - Adolescent Health Initiative
- **SEXUALLY TRANSMITTED DISEASES**
- **CERVICAL CANCER**
- **FUNDING FOR FAMILY PLANNING SERVICES**
- **BREAST AND CERVICAL CANCER SCREENING**

### **ACCESS TO HEALTH CARE**

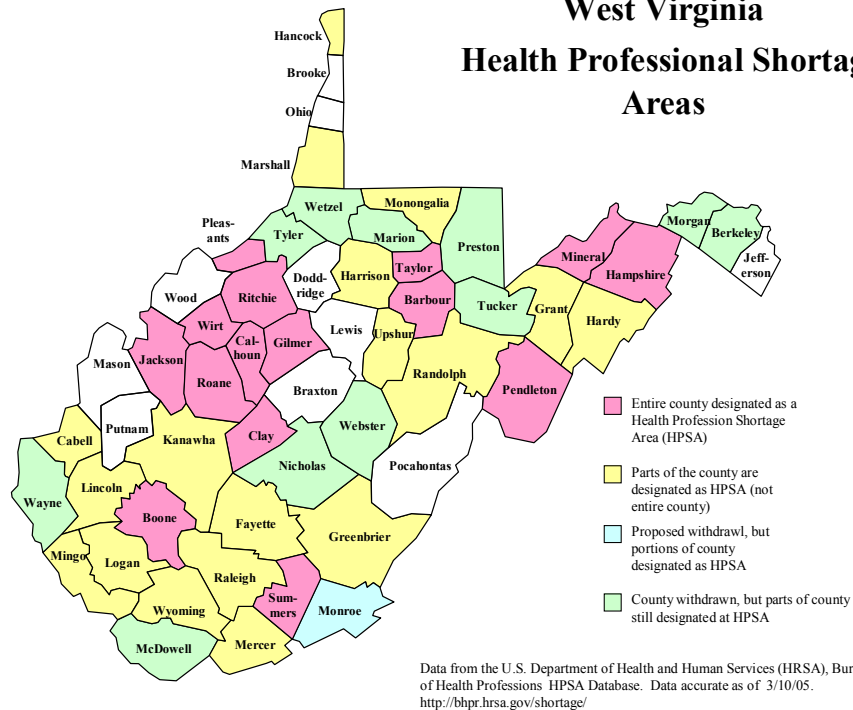
West Virginia is surrounded by Pennsylvania, Maryland, Virginia, Ohio, and Kentucky and is commonly referred to as a South Atlantic state. The second most rural state in the nation, 20 of West Virginia's 55 counties are 100% rural according to the Census Bureau definition, with an additional 14 more than 75% rural. Winding secondary roads connect the majority of the state's population, with little to no public transportation available between many of the small, isolated towns. Therein lies the single most often cited issue with access to health care for many of the state's residents.

Thirty-seven of West Virginia's 55 counties are classified as being medically underserved areas with an additional 12 counties classified as partially underserved. According to the West Virginia Department of Health and Human Resources, Bureau for Public Health, Office of Epidemiology and Health Promotion, the current number of licensed physicians in West Virginia was 4,067 as of September 28, 2004. Of these 3,515 (86 percent) were licensed medical doctors and 522 (14 percent) were licensed osteopathic physicians.



The unequal distribution of professional health care manpower, particularly in rural areas, is problematic for the state. As of September 2004, forty of West Virginia's fifty-five counties (73 percent) were fully or partially designated by the federal government as Health Professional Shortage Areas. This designation means that the ratio of primary care physicians to the total population is less than 1:3500.

## West Virginia Health Professional Shortage Areas



### *Capacity to Address Needs:*

Eighty-one (81) primary care centers are located in the forty-nine (49) counties federally designated in whole or in part as Medically Underserved Area or Medically Underserved Populations (MCUAs/MUPs), thus making them eligible for federal assistance. There are fourteen (14) free clinics, otherwise known as Health Rights; eleven (11) of these are state funded. They offer care to uninsured West Virginians whose income is at or below 150% of the federal poverty level (FLP). These free clinics receive no federal funding. The primary care centers serve as the principal source of primary medical services in the rural Medically Underserved Areas of West Virginia, and are often the only source of medical care in many isolated rural communities.

Primary care centers, supported with state or federal funds, must see all patients regardless of their ability to pay. Beginning in FY 1982-83, the state began funding primary care centers through competitive applications to help centers survive financial difficulty associated with the provision of uncompensated care. State funding of primary care centers has curtailed closures and allowed some centers in financial difficulty to remain open.

In mid-March, West Virginia passed legislation intended to enable more small businesses to provide insurance coverage to their employees. The State Coverage Initiative (SCI) Program helped to make the proposed expansion possible by providing the state with a \$1.36 million demonstration grant in 2003 which was intended to support the design and implementation of a new coverage program.

The new law creates a public/private partnership between the West Virginia Public Employees Insurance Agency (PEIA) and insurance companies. The private carriers will be given access to PEIA's reimbursement rates, enabling them to sell coverage that is more affordable than they have been able to sell previously. In fact, the state expects the new small business coverage cost to be 20-25 percent below the usual market rate – which will ultimately expand the pool of insured working West Virginians. During the fall, the West Virginia Health Care Authority reached out to health care providers and insurance carriers to solicit participation in the program.

The new coverage plan will be open to small businesses with 2 to 50 employees who have had no coverage for 12 consecutive months. Employers will be required to pay a minimum of 50 percent of the premium cost for employee-only coverage and 75 percent of eligible employees must participate. Participating carriers must demonstrate a minimum anticipated medical loss ratio of 77 percent to be eligible for a rate increase after the first year of the plan (the current requirement is 73 percent). As of December 2004, one carrier has filed with the state to offer the new product which was available January 1, 2005.

**Lack of Health Insurance, by State**  
**Rank Order – Best to Worst**

<b>Rank 1-50</b>	<b>State</b>	<b>Percentage Of Population</b>
1	MN	8.7
2	VT	9.5
3	HI	10.1
3	RI	10.2
5	NH	10.3
6	CT	10.4
6	ME	10.4
8	MA	10.7
9	MI	10.9
9	ND	10.9
9	WI	10.9
9	KS	11.0
9	MO	11.0
14	DE	11.1
15	IA	11.3
15	NE	11.3
17	PA	11.4
18	OH	12.1
18	SD	12.2
20	UT	12.7
21	VA	13.0
22	TN	13.2
23	IN	13.9
23	MD	13.9
25	KY	14.0
25	NJ	14.0
27	AL	14.2
28	IL	14.4
28	SC	14.4
30	NY	15.1
31	WA	15.5
32	WY	15.9
33	GA	16.4
34	WV	16.6
35	AZ	17.0
36	CO	17.2
36	OR	17.2
38	NC	17.3
39	AR	17.4
40	MS	17.9
41	FL	18.2
42	CA	18.4
43	ID	18.6
44	AK	18.9
44	NV	18.9
46	MT	19.4
47	OK	20.4
48	LA	20.6
49	NM	22.1
50	TX	24.6

Source: 2003 Data, Current Population  
Survey, March 2004, U.S. Census Bureau

### *Capacity to Address Needs Continued:*

The Recrutable Community Program (RCP) was initiated in WV in 1998 and focuses on increasing a rural community's recruiting potential. The original RCP strategies included:

- (1) Enhancing the ability of rural communities to recruit medical providers through community development and increased knowledge of recruitment and retention issues.
- (2) Placing primary care resident, nurse practitioner and physician assistant trainees in selected communities to make them more familiar with the rewards and challenges of practicing in rural areas.

To further stabilize West Virginia's rural health care infrastructure and improve access to quality health care services, the RCP has developed a collaborative relationship with the Division of Rural Health (DRH) within the Department of Health and Human Resources, Bureau for Public Health, Office of Community Health Systems. The DRH serves as the focal point for rural health issues in West Virginia and contributes to innovative approaches for addressing rural health care needs of West Virginians. The Division collaboratively plans and develops policy, provides technical assistance and provides statewide coordination of rural health activities. The collaborative process between RCP and DRH involves eliminating duplication while effectively maintaining access to community development expertise for rural communities.

The result of the collaborative partnership was the transfer of the Recrutable Community Program from WVU Department of Family Medicine to the Bureau for Public Health as an established Program within the DRH. The RCP brings to the table links to the community and the established community development methodology that is now partnered with the DRH structural and financial stability.

Cornerstones of the Program have been and will continue to be:

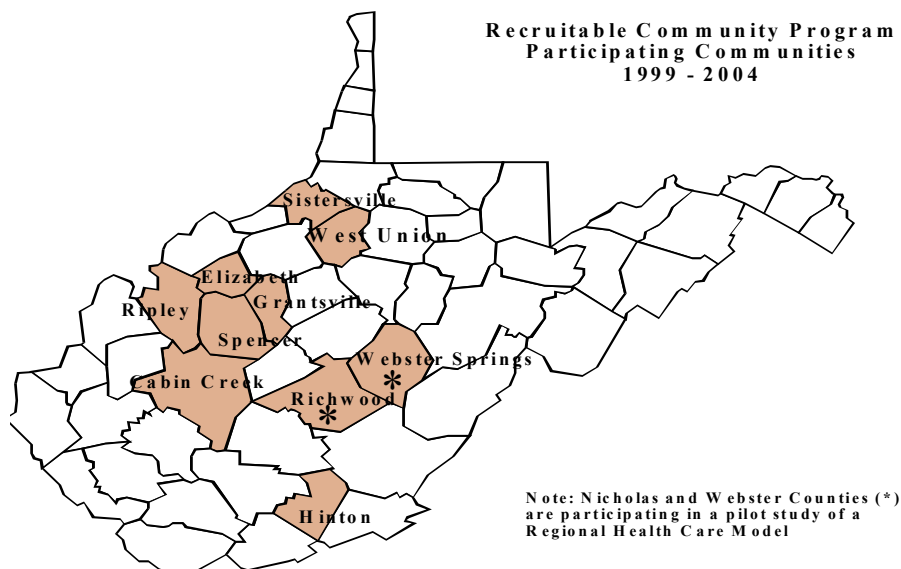
- Frequent interaction between participant communities and program personnel who work with the communities providing technical assistance and maintaining focus as they work through the various RCP components;
- Visits to participating communities initially by a "first impression" team that assesses the appearance of the community and provides recommendations for enhancing its image to recruits and others, and subsequently form a "community design" team that makes assessments and recommendations for general community development and for enhancement of community recruiting potential;
- Recruitment workshops with a rural focus; and

- Continued technical assistance to the community recruitment boards of the participant communities.

The RCP has been successful in developing collaborative relationships among academic institutions, state and national experts, key volunteers and communities. Key partners include:

- West Virginia University Extension Service
- West Virginia University School of Medicine, Department of Family Medicine
- West Virginia University Area Health Education Centers
- Department of Health and Human Resources, Bureau for Public Health, Divisions of Rural Health, Primary Care and Recruitment
- The Center for Rural Health Development
- West Virginia Rural Health Access Program
- West Virginia University Division of Resource Management

The high cost of medical education is resulting in more interest among students and graduates about financial incentive programs to practice in West Virginia. The situation is being exacerbated by the financial crisis at the medical schools due to budget cuts, since increasing tuition and fees is one of many strategies being used to address budget shortfalls. One of the challenges we hope to address through our collaborative efforts is an increase in financial incentive dollars for the number of qualified applicants. Recruitment and retention of qualified medical personnel in very rural communities in West Virginia is a priority of the RCP.



## **PREMATURITY AND LOW BIRTH WEIGHT IN WEST VIRGINIA**

West Virginia has struggled with the incidence of low birth weight infants. Birth weight is the single most important predictor of infant survival. Low birth weight is defined as a weight of less than 2,500 grams at birth and may result from preterm birth (before 37 weeks) or poor fetal growth for a given duration of pregnancy (intrauterine growth retardation) or both. In the U.S. most infant deaths are associated with low birth weight.

Tracking the rise in the proportion of births that are preterm (those occurring before 37 completed weeks of gestation) and identifying other risk factors such as low income levels and education affirms that focusing attention on government sponsored patients (Medicaid/TitleV) is important. According to Vital Statistics data, between 1991 and 2000, the percent of all mothers in WV receiving adequate or adequate plus prenatal care increased 16%.

Between 1992 and 2002, the rate of infants born preterm in WV increased 30%. In 2001, charges in the U.S. for hospital stays for infants with any diagnosis of prematurity were estimated at \$13.6 billion. Risk factors for preterm birth and low birth weight include: previous preterm and/or low birth weight birth, multiple births, smoking, unplanned pregnancy, infections, poor nutrition, lack of access to adequate and early prenatal care, harmful substance abuse and domestic violence.

There were a total of 1,814 low birth weight babies (those weighing less than 2,500 grams or 5.5 pounds) born to West Virginia residents in 2003, 8.7% of all births. Of the 1,797 low birth weight infants with known gestational age, 1,253 or 69.7% were preterm babies born before 37 weeks of gestation. (Of all 2003 resident births with a known gestational age, 11.7% were preterm babies.) Of the births with known birth weight, 11.9% of babies born to black mothers and 8.5% of babies born to white mothers were low birth weight. Nationally, 7.9% of all infants weighed less than 2,500 grams at birth in 2003; 7.0% of white infants and 13.5% of black infants were of low birth weight. Eighty-five point eight percent (85.8%) of West Virginia mothers with known prenatal care began their care during the first trimester of pregnancy, compared to 84.3% of mothers nationwide in 2003. Among those with known prenatal care, 86.3% of the white mothers began care during the first trimester; 73.4% of black mothers did so. (U.S. figures show 85.5% of white mothers and 76.1% of black mothers). No prenatal care was received by 0.6% of white mothers and by 1.2% of black mothers. Over one-fourth (26.2%) of the 20,986 births in 2003 were to mothers who smoked during their pregnancies, while 0.3% of births were to women who used alcohol. National figures show that 11.0% of women giving birth reported smoking during pregnancy and 0.8% used alcohol. Of the state mothers who reported smoking during pregnancy, 13.3% of the babies born were low birth weight, compared to 7.0% for non-smoking mothers. U.S. statistics show 12.2% births to smoking mothers were low birth weight and 7.5% for non-smoking mothers. Over thirty percent of 2003 state births were delivered by



Cesarean section, compared to a national rate of 27.6%. One or more complications of labor and/or delivery were reported for 32.8% of deliveries in the State in 2003.

**Birth Weight by Age of Mother  
West Virginia Resident Births – 2003**

Birth Weight	Age of Mother										Total
	10-14 Years	15-17 Years	18-19 Years	20-24 Years	25-29 Years	30-34 Years	35-39 Years	40-44 Years	45 and Over	Unknown	
Less than 1,000 Grams (Less than 2.205 lbs.)	2	6	22	37	35	20	8	4	0	0	134
1,000 – 1,499 Grams (2.205 – 3.305 lbs.)	0	2	22	53	28	28	16	5	0	0	154
1,500 – 1,999 Grams (3.307 – 4.407 lbs.)	0	10	35	109	90	52	23	4	4	0	327
2,000 – 2,499 Grams (4.409 – 5.509 lbs.)	0	43	115	428	298	194	91	25	5	0	1,199
2,500 – 2,999 Grams (5.512 – 6.612 lbs.)	9	160	419	1,406	1,056	621	258	50	2	1	3,982
3,000 – 3,499 Grams (6.614 – 7.714 lbs.)	15	297	701	2,692	2,268	1,382	522	92	7	0	7,976
3,500 – 3,999 Grams (7.716 – 8.816 lbs.)	7	163	426	1,656	1,639	1,158	431	71	6	0	5,557
4,000 – 4,499 Grams (8.819 – 9.919 lbs.)	1	26	83	387	420	337	135	24	1	0	1,414
4,500 or more Grams (9.921 or more lbs.)	0	1	7	51	79	55	18	5	0	0	216
Unknown	0	3	1	1	3	5	8	4	2	0	27
<b>TOTAL</b>	<b>34</b>	<b>711</b>	<b>1,831</b>	<b>6,820</b>	<b>5,916</b>	<b>3,852</b>	<b>1,510</b>	<b>284</b>	<b>27</b>	<b>1</b>	<b>20,986</b>

West Virginia Bureau for Public Health – Health Statistics Center, 2005

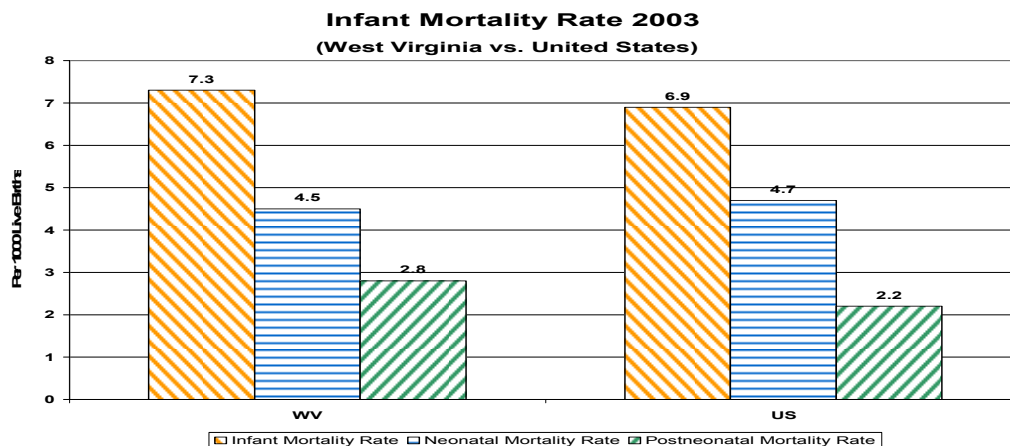
The OMCFH has a strong collaborative partnership with the WV March Of Dimes whose mission is to improve infant health by preventing birth defects and infant mortality. Prematurity/low birth weight is the leading cause of death in the first month of life. In addition to mortality, prematurity is a major determinant of illness and disability among infants, including developmental delays, chronic respiratory problems, and vision and hearing impairment. To address this growing problem, the March of Dimes has

committed to a five year national prematurity research, awareness, and education campaign to help families have healthier babies.

WV Vital Statistics data prove that although access to 1st trimester prenatal care in WV is at about 86%, the state continues to experience a higher than average number of babies born preterm and/or low birth weight. Because of this continued upward trend in WV for the last several years, there is much work to be done in the arena of prenatal care and education. Although for most preterm births the underlying cause is undetermined, there are many identified risks which are known and can improve birth outcomes through education and intervention. The Birth Defects Surveillance System located within the Research, Evaluation and Planning Division of OMCFH now collects infant and mother information on preterm and low birth weight babies in order to track incidence and note maternal behaviors that may be contributing factors to birth outcomes.

### **NEONATAL/POST-NEONATAL/INFANT DEATHS**

According to the WV Health Statistics Center the number of neonatal deaths dropped by 14, from 109 in 2002 to 95 in 2003; the neonatal death rate also decreased from 5.3 deaths among infants under 28 days per 1,000 live births in 2002 to 4.5 in 2003. Neonatal deaths comprised 62.1% of all West Virginia resident infant deaths in 2003, compared to 58.0% in 2002. The rate of post neonatal deaths decreased from 3.8 deaths 1,000 neonatal survivors in 2002 to 2.8 in 2003. The 2002 U.S. neonatal death rate was 4.7, while the post neonatal rate was 2.2 deaths per 1,000 neonatal survivors.



#### **Infant Deaths**

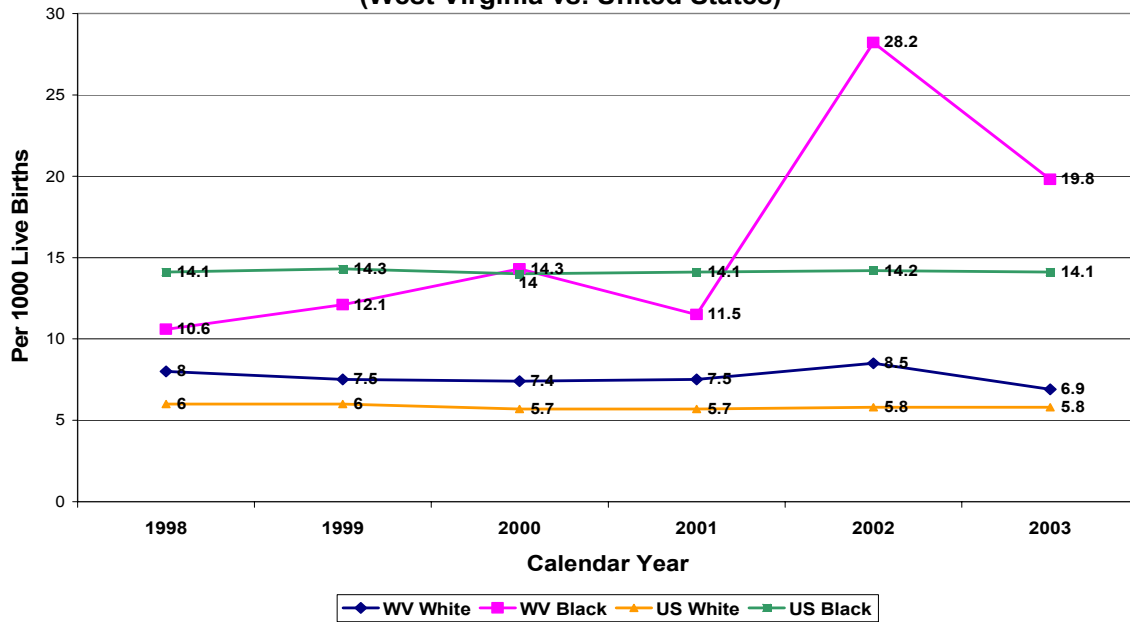
Deaths of infants under one year of age dropped substantially, from 188 in 2002 to 153 in 2003. West Virginia's infant mortality rate also decreased, from 9.1 per 1,000 live births in 2002 to 7.3. The U.S. preliminary 2003 infant mortality rate was 6.9, same as 2002.

The following table shows the decline in the national and state infant mortality rates from 1950 through 2003.

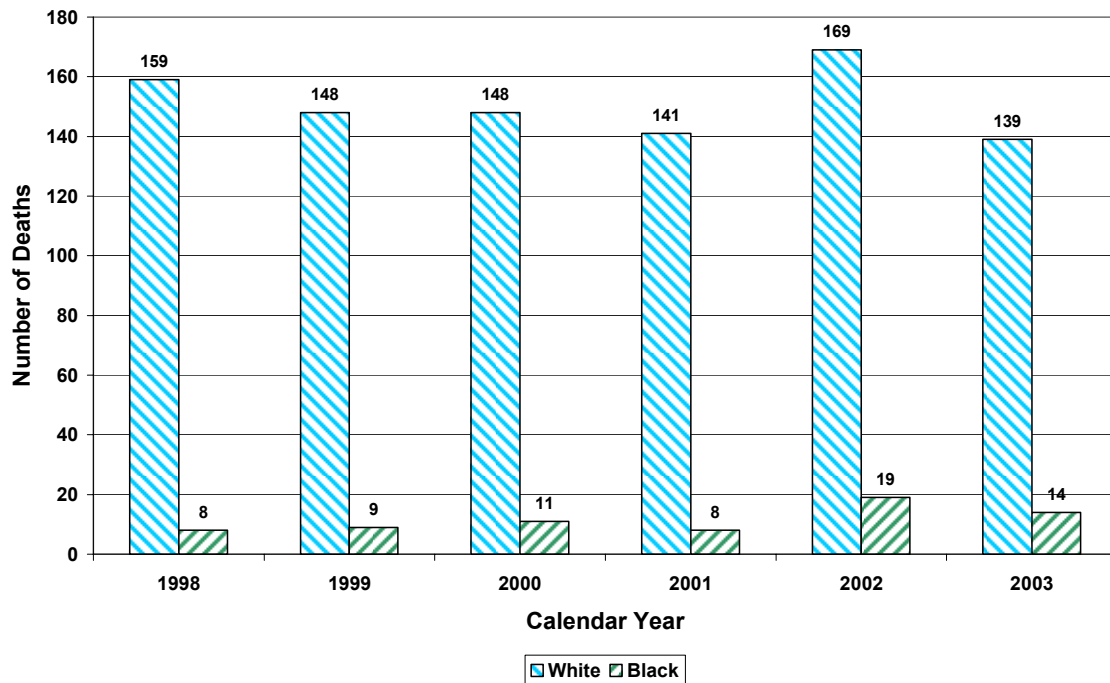
**1950 – 2003 Infant Mortality  
West Virginia and United States  
(Number and Rate per 1,000 Live Births)**

<b>YEAR</b>	<b>WEST VIRGINIA</b>	<b>UNITED STATES</b>
<b>1950</b>	<b>31.4</b>	<b>29.2</b>
<b>1955</b>	<b>27.1</b>	<b>26.4</b>
<b>1960</b>	<b>25.3</b>	<b>26.0</b>
<b>1965</b>	<b>27.1</b>	<b>24.5</b>
<b>1970</b>	<b>23.3</b>	<b>20.0</b>
<b>1975</b>	<b>18.3</b>	<b>16.1</b>
<b>1980</b>	<b>11.8</b>	<b>12.6</b>
<b>1985</b>	<b>10.7</b>	<b>10.6</b>
<b>1990</b>	<b>9.8</b>	<b>9.1</b>
<b>1995</b>	<b>7.6</b>	<b>7.5</b>
<b>1996</b>	<b>7.2</b>	<b>7.2</b>
<b>1997</b>	<b>9.5</b>	<b>7.2</b>
<b>1998</b>	<b>8.1</b>	<b>7.2</b>
<b>1999</b>	<b>7.6</b>	<b>7.1</b>
<b>2000</b>	<b>7.6</b>	<b>6.9</b>
<b>2001</b>	<b>7.3</b>	<b>6.9</b>
<b>2002</b>	<b>9.1</b>	<b>6.9</b>
<b>2003</b>	<b>7.3</b>	<b>6.9</b>

## Infant Mortality by Race (West Virginia vs. United States)

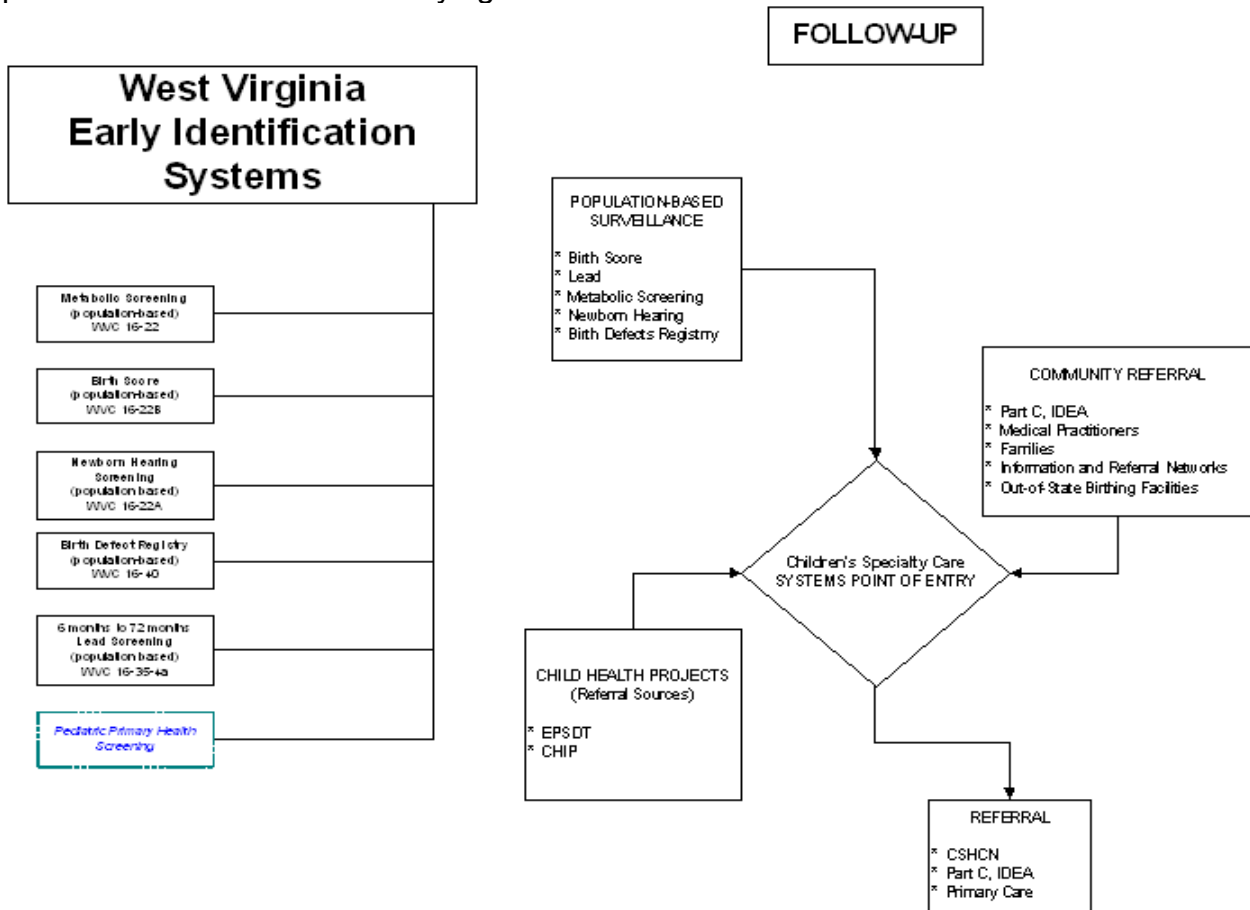


## West Virginia Number of Infant Deaths by Race



## Capacity to Address Needs:

The West Virginia OMCFH has established an early identification system that has proven to be effective in identifying infants and children in need of service.



Medicaid is a major source of financing for health care services provided to pregnant women, infants and children. According to data from the WV Health Statistics Center, in 2003, 53.2% of births in WV were paid for by Medicaid. Due to economic circumstances in WV the percentage of Medicaid eligible families has continued to increase. While pregnant women and non-disabled, non-elderly adults and children in WV make up almost 67% of Medicaid enrollees in 2000, they accounted for only 21% of spending for these groups.

WV has experienced numerous funding cuts in the reimbursement rates for service provision in the last few years. West Virginia's perinatal program, Right From the Start (RFTS) is a partnership between the OMCFH and Medicaid to provide access to early and adequate prenatal care to low income pregnant women and infants. Financial restraints have made it difficult for service delivery.

The following chart shows the decline in services paid for and reimbursement from 1989 to 2004:

**Right From The Start Project  
Bureau for Public Health  
West Virginia Department of Health and Human Resources**

Timeline	Type of Coverage	Allowable Units of Service	Cost/Service	Total Cost Potential
<b>1989 Project Initiation Prenatal</b>	POPRAS	1/case	\$104.00 (1 <sup>st</sup> Trimester) \$52.00 (2 or 3 Trimesters)	<b>\$104.00</b> or <b>\$52.00</b>
	Initial Assessment	1/case	\$96.00	<b>\$96.00</b>
	Care Coordination	15 minute units – no limit (32 average per case)	\$12.00	<b>\$384.00</b>
	Psycho Social Assessment	1/3 months	\$47.60	<b>\$142.80</b>
	Pyscho Social Services	32 – 15 minute units/Prenatal Period/case	\$20.00	<b>\$640.00</b>
		32 – 15 minute units/Postpartum Period/case	\$20.00	<b>\$640.00</b>
	Preventive Education	32 – 15 minute units/case	\$12.00	<b>\$384.00</b>
	Parenting Education	32 – 15 minute units/case	\$12.00	<b>\$384.00</b>
	Childbirth Education	7 – 2 hour sessions/case	\$12.00	<b>\$84.00</b>
	Nutrition Education	32 – 15 minute units/Prenatal Period/case	\$16.00	<b>\$512.00</b>
		32 – 15 minute units/Postpartum Period/case	\$16.00	<b>\$512.00</b>
	DCC Mileage Reimbursement	15 minute units travel time (care coordination face-to-face visits only)	\$12.00 per unit	<b>\$192.00</b> 8 visits @ 2 units per trip
			<b>Total</b>	<b>\$4074.80</b> or <b>\$4022.80</b>
<b>1990 High Risk Infants Care Coordination</b>	Initial Assessment	1/ case	\$96.00	<b>\$96.00</b>
	Care Coordination	15 Minute units – no limit	\$12.00	<b>384.00</b>
	DCC Mileage Reimbursement	15 minute units travel time (care coordination face-to-face visits only)	\$12.00 per unit	<b>\$192.00</b> 8 visits @ 2 units per trip
			<b>Total</b>	<b>\$672.00</b>
<b>1993 Prenatal Change in Travel Reimbursement</b>	DCC Mileage Reimbursement	28.5 cents/per mile care coordination face-to-face visits only)	28.5 cents/per mile	<b>\$34.20</b> 8 visits @ 15 miles per trip
			<b>Total</b>	<b>\$3916.20</b> or <b>\$3865.00</b>
<b>1993 Infant Change in Travel Reimbursement</b>	DCC Mileage Reimbursement	28.5 cents/per mile care coordination face-to-face visits only)	28.5 cents/per mile	<b>\$34.20</b> 8 visits @ 15 miles per trip

Timeline	Type of Coverage	Allowable Units of Service	Cost/Service	Total Cost Potential
			<b>Total</b>	<b>\$514.20</b>
<b>1998 POPRAS Discontinued/PRSI initiated</b>	PRSI	1/case	\$6.12	<b>\$6.12</b>
	Initial Assessment	1/case	\$96.00	<b>\$96.00</b>
	Care Coordination	15 minute units-no limit (32 average per case)	\$12.00	<b>\$384.00</b>
	Psycho Social Assessment	1/3 months	\$47.60	<b>\$142.80</b>
	Psycho Social Services	32 – 15 minute units/Prenatal Period/case	\$20.00	<b>\$640.00</b>
		32 – 15 minute units/Postpartum Period/case	\$20.00	<b>\$640.00</b>
	Preventive Education	32 – 15 minute units/case	\$12.00	<b>\$384.00</b>
	Parenting Education	32 – 15 minute units/case	\$12.00	<b>\$384.00</b>
	Childbirth Education	7 – 2 hour sessions/case	\$12.00	<b>\$84.00</b>
	Nutritional Education	32 – 15 minute units/Prenatal Period/case	\$16.00	<b>\$512.00</b>
		32 – 15 minute units/Postpartum Period/case	\$16.00	<b>\$512.00</b>
	DCC Mileage Reimbursement	32.5 cents/per mile (care coordination face-to-face visits only)	32.5 cents per mile	<b>\$39.00</b> 8 visits @ 15 miles per trip
			<b>Total</b>	<b>\$3823.92</b>
<b>2000</b>	PRSI	1/case	\$6.12	<b>\$6.12</b>
	Initial Assessment	1/case	\$96.00	<b>\$96.00</b>
	Care Coordination	15 minute units-no limit (32 average per case)	\$12.00	<b>\$384.00</b>
	Psycho Social Assessment	Discontinued	\$0.00	<b>\$0.00</b>
	Psycho Social Services	Discontinued	\$0.00	<b>\$0.00</b>
	Preventive Education	32 – 15 minute units/case	\$12.00	<b>\$384.00</b>
	Parenting Education	32 – 15 minute units/case	\$12.00	<b>\$384.00</b>
	Childbirth Education	7 – 2 hour sessions/case	\$12.00	<b>\$84.00</b>
	Nutritional Education	32 – 15 minute units/Prenatal Period/case	\$16.00	<b>\$512.00</b>
		32 – 15 minute units/Postpartum Period/case	\$16.00	<b>\$512.00</b>
	DCC Mileage Reimbursement	33 cents/per mile (care coordination face-to-face visits only)	33 cents per mile	<b>\$39.60</b> 8 visits @ 15 miles per trip
			<b>Total</b>	<b>\$2401.72</b>
<b>2003 Reduction in Enhanced Services</b>	PRSI	1/case	\$6.12	<b>\$6.12</b>
	Initial Assessment	1/case	\$96.00	<b>\$96.00</b>
	Care Coordination	15 minute units-no limit (32 average per case)	\$12.00	<b>\$384.00</b>
	Preventive Education	1 session/day – Limit 20/9 months	\$12.00	<b>\$240.00</b>
	Parenting Education	1 session/day – Limit 20/9 months	\$12.00	<b>\$240.00</b>
	Childbirth Education	1 session/day – Limit 7/9 months	\$12.00	<b>\$84.00</b>

Timeline	Type of Coverage	Allowable Units of Service	Cost/Service	Total Cost Potential
	Nutritional Education	1 session/day – Limit 44/9 months	\$18.00	<b>\$792.00</b>
	DCC Mileage Reimbursement	37.5 cents/per mile (care coordination face-to-face visits only)	37.5 cents per mile	<b>\$45.00</b> 8 visits @ 15 miles per trip
			<b>Total</b>	<b>\$1887.12</b>
<b>2004 Prenatal</b>	PRSI	1/case	Discontinued	<b>\$0.00</b>
	Initial Assessment	1/case	\$96.00	<b>\$96.00</b>
	Care Coordination	15 minute units-no limit (32 average per case)	\$12.78	<b>\$408.96</b>
	Preventive Education	1 session/day – Limit 20/9 months	\$12.00	<b>\$240.00</b>
	Parenting Education	1 session/day – Limit 20/9 months	\$12.00	<b>\$240.00</b>
	Childbirth Education	1 session/day – Limit 7/9 months	\$12.00	<b>\$84.00</b>
	Nutritional Education	1 session/day – Limit 44/9 months	\$18.00	<b>\$792.00</b>
	DCC Mileage Reimbursement	Discontinued	\$0.00	<b>\$0.00</b>
			<b>Total</b>	<b>\$1860.96</b>
<b>2004 Infants</b>	Initial Assessment	1/case	Discontinued	<b>\$0.00</b>
	Care Coordination	15 minute units-no limit (32 average per case)	\$12.78	<b>\$408.96</b>
			<b>Total</b>	<b>\$408.96</b>

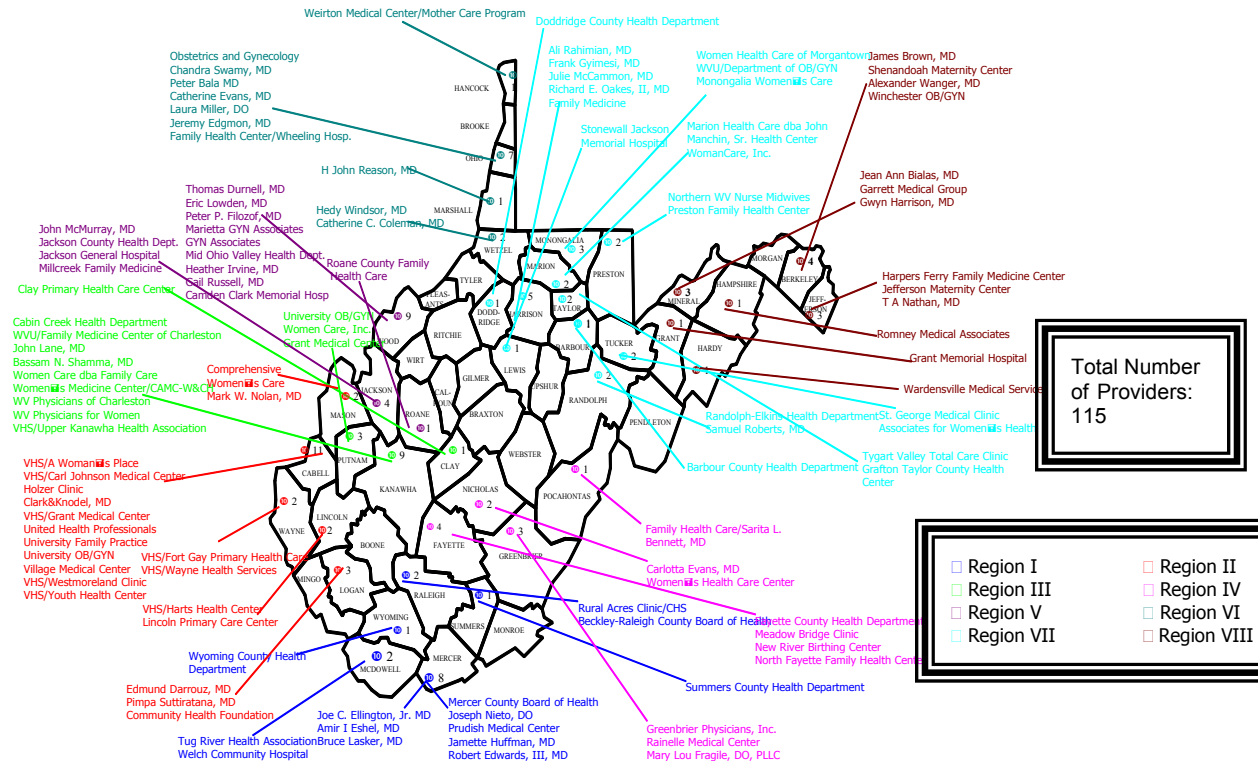
The OMC FH Obstetrical Care Services also provides some coverage for prenatal care to WV pregnant women who are uninsured or underinsured and are above the income guidelines for Medicaid. These pregnant women may qualify for some assistance for their prenatal care if they are a WV resident, fall between 150-185% of the Federal Poverty Level, are a pregnant teen age 19 or under or a non-citizen. Under this Title V funded program, women who have no funding source for prenatal care coverage or have not yet been approved for coverage can receive assistance for payment of their first prenatal visit, an ultrasound and routine laboratory procedures if ordered on the first visit.



# CONTRACTED OBSTETRICAL PROVIDERS CALENDAR YEAR 2004



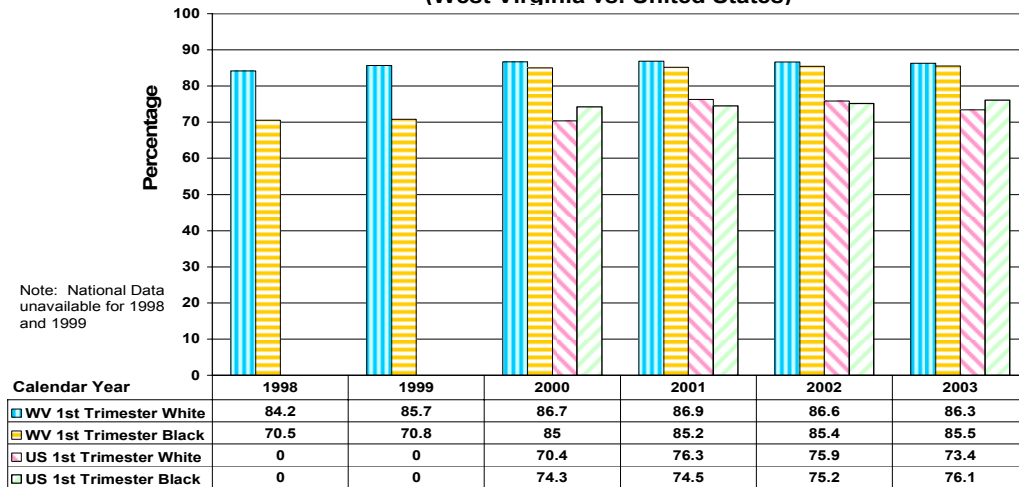
Office of Maternal,  
Child and Family Health



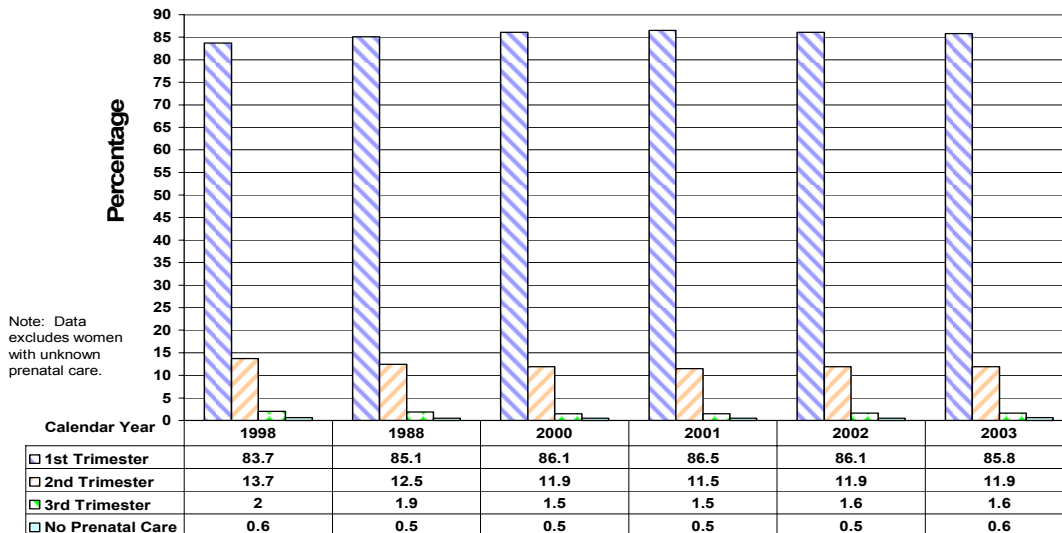
Prepared by Perinatal Programs  
Data Source: Right From The Start Project

There are approximately 84 community agencies throughout West Virginia who have contracted with the OMC FH to provide care coordination and enhanced education services to high risk pregnant women and infants. Licensed nurses and social workers assist these populations with access to early and adequate prenatal/health care. Besides these providers, obstetricians, nurse practitioners, nurse midwives, and family practice physicians in WV and WV's bordering states contract with the OMC FH to provide obstetrical and delivery care to pregnant women in WV according to ACOG national standards. This network of providers has offered services to eligible WV families since 1989 and continue to do so today even though reimbursement for services is inadequate. Providers are now expressing concern about their ability to continue to provide prenatal care for this high risk population because of financial losses. Despite these concerns, the network to provide care to pregnant women and infants up to age one year exists statewide and has been proven effective by data which shows that women have a rate of 86% access to 1<sup>st</sup> trimester prenatal care in WV.

### 1st Trimester Prenatal Care by Race (West Virginia vs. United States)



### West Virginia Prenatal Care by Year



## NEWBORN METABOLIC SCREENING

Newborn Metabolic Screening is an important state-based public health program that began over 40 years ago. States and territories mandate newborn screening of all infants born within their jurisdiction for certain disorders that may not otherwise be detected before developmental disability or death occurs. WV currently tests for Hemoglobinopathies, Galactosemia, Hypothyroidism and Phenylketonuria (PKU).

The goal is to adopt the twenty-nine (29) universal newborn metabolic test panels as recommended in 2005 by the Secretary's Advisory Committee on Heritable Disorders and Genetic Diseases, established by the U.S. Department of Health and Human Services.

In an effort to understand how additional testing for disorders would affect WV, the Department convened an expert panel composed of pediatricians, geneticists, hospital administrators, etc. to make recommendations about expanded screening and to identify the components necessary for a comprehensive screening system that includes screening, short term follow-up, diagnosis, treatment, and evaluation.

It is the recommendation of the Newborn Screening Committee that WV incrementally expand the panel, to ensure state resources are in place to support the effort. A report of the State's plan follows.

*Capacity to Address Needs:*

**WV Newborn Metabolic Screening Expansion Plan  
FY 05-06**

ISSUE	ACTION
Effective 7/01/05	<p>Current screening panel is maintained. Current test panel includes Congenital Hypothyroidism, Phenylketonuria (PKU), Galactosemia, and Hemoglobinopathies, including Sick Cell Anemia.</p> <p>The change in the system, and how it operates, will be that all birthing facilities, outpatient and free-standing laboratories, and physicians (who provide secondary screening tests) will be charged for each kit obtained from the OLS (State Lab).</p> <p>The charge for the kits, as per the Fee-for-Service rule, 64 CSR, will be \$28.00.</p> <p>BPH will establish in policy the expectation that payment for test kits will accompany the kit order.</p> <p>The BPH will proceed as follows:</p> <ul style="list-style-type: none"> <li>• OLS will handle billing and mailing and payment process for kits.</li> <li>• OLS will develop/revise test kit order form that specifies payment must accompany order.</li> <li>• Alert BMS of policy change, and that repeat tests will be directly billed to Unisys. Charge of initial tests will be assimilated into DRG at birthing facilities. A copy of the cost projections, Phase I, for BMS is Attachment II.</li> <li>• OMC FH will develop provider and public/patient informing materials.</li> <li>• Policy guidance will be developed by MCFH that addresses repeat testing, since this <u>does not</u> always occur at birthing facility.</li> <li>• Special revenue account will be established to handle collected fees. <b>Assignee:</b> BPH/Budget Office.</li> </ul>
<b>PHASE I:</b>  Incremental Expansion of	Current test panel includes Congenital Hypothyroidism, Phenylketonuria (PKU), Galactosemia, and Hemoglobinopathies, including Sick Cell Anemia.

ISSUE	ACTION
<p>Screening Panel</p> <p>Tentative Date: 07/06</p>	<p>Phase I expansion will include all the above tests plus:</p> <ul style="list-style-type: none"> <li>• Medium-chain Acyl-CoA Dehydrogenase Deficiency (MCAD)</li> <li>• Congenital Adrenal Hyperplasia (CAH)</li> <li>• Maple Syrup (Urine) Disease (MSUD)</li> <li>• Biotinidase Deficiency (BIOT)</li> <li>• Homocystinuria (HCY)</li> </ul> <p>Decision tree for selecting the Phase I panel:</p> <ul style="list-style-type: none"> <li>• Approach delivers greatest good to the greatest number of people. These are tests that have higher incidence levels.</li> <li>• Allows the state to gradually develop capacity, resulting in a system that is coordinated and comprehensive that includes education, screening, follow-up, diagnosis, and treatment management.</li> </ul>
<p>Phase I Implementation Process</p>	<ul style="list-style-type: none"> <li>• Rent the equipment necessary to perform the tests for OLS. <b>Assignee:</b> OLS</li> <li>• Preliminary discussion about all procedural changes listed below with the West Virginia Hospital Association. <b>Assignee:</b> OMCFH</li> <li>• Issue public health screening policy identifying new test protocols and affirming OLS responsibility for all testing. <b>Assignee:</b> OMCFH/Health Officer</li> <li>• Alert major insurers via the Insurance Commissioner of this change. <b>Assignee:</b> OMCFH</li> <li>• Establish a fee for managing the system (testing, follow-up, etc.) including attention to any changes in the fee-for-service rule. <b>Assignee:</b> BPH/Administration/OLS</li> <li>• Alert BMS to the billing strategy and provide cost projections; see projections for BMS, Phase I expansion, Attachment II. <b>Assignee:</b> OMCFH</li> <li>• Alert all birthing facilities, including their outpatient labs and medical practitioners serving children, that there will be a fee applied to each test specimen kit ordered, Attachment III.</li> </ul>

ISSUE	ACTION
	<p><b>Assignee:</b> OMCFH</p> <p><b>Cue:</b> Birthing facilities will bill each payor for this service – PEIA, Title XIX, Blue Cross-Blue Shield, etc.</p> <ul style="list-style-type: none"> <li>• Develop patient informing guidance/talking points for use by case managers and others serving pregnant women. <b>Assignee:</b> OMCFH</li> <li>• Develop web-based guidance portraying changes to the system and identifying expert medical resources. <b>Assignee:</b> OMCFH</li> <li>• Educate pediatric practitioner community about protocol changes, resources, etc. as part of medical home. <b>Assignee:</b> OMCFH/WVU Genetics</li> </ul>
Phase I Evaluation	<ul style="list-style-type: none"> <li>• Track the number of test kits and tests to conclusion for federal reporting purposes, to include diagnosis and follow-up. <b>Assignee:</b> OLS</li> <li>• Provide evaluation/assessment surveys to practitioners about effectiveness of resource guidance and technical assistance. <b>Assignee:</b> OMCFH</li> </ul>
Phase II Long Range Plan  Tentative Date: 07/08	<p>Expand screening panel to include tests recommended by the Secretary's Advisory on Heritable Diseases and Genetic Disorders in Children.</p> <p>Plan and cost projections pending, along with other project detail.</p>

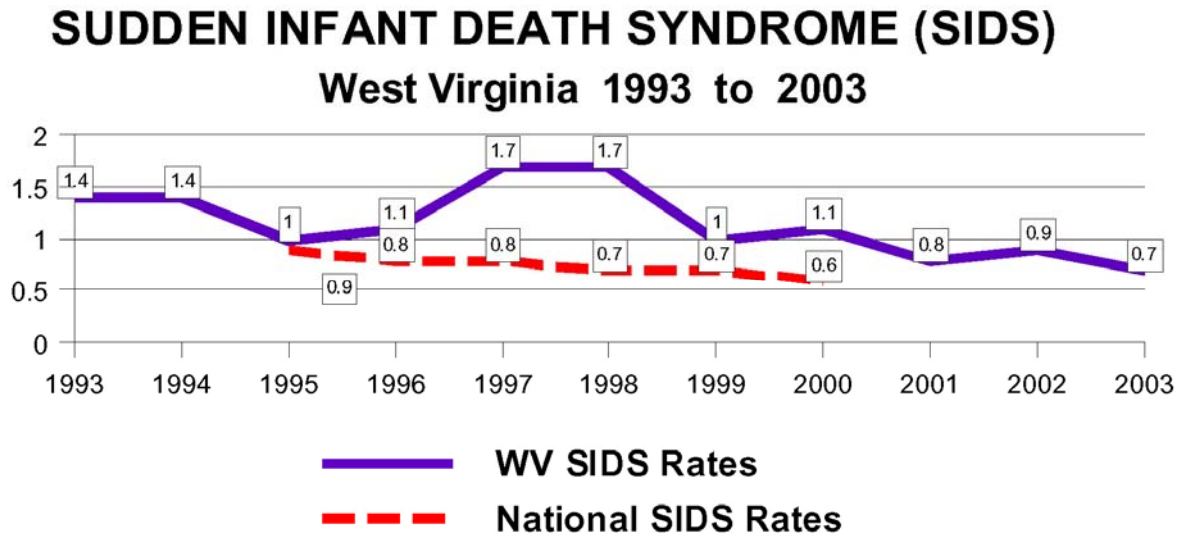
### **SUDDEN INFANT DEATH SYNDROME (SIDS)**

Sudden Infant Death Syndrome (SIDS) is the sudden and unexplained death of an infant under one year of age. Nationally, SIDS is a major cause of death in all babies from one month to one year of age. Death is sudden and unpredictable and, in most cases, the baby seems healthy. Death occurs quickly and usually during a sleep period.

In West Virginia, during calendar year 2003, there were fifteen (15) deaths attributed to Sudden Infant Death Syndrome (SIDS), down from nineteen (19) reported in 2002. Considering the number of deaths, the number of SIDS deaths equates to approximately ten percent (10%) of all infant deaths in both 2002 and 2003. However, due to recent changes nationally in criteria used in medical examiner's offices to determine cause of death, the number of SIDS deaths decreased and, correspondingly, the number of undetermined death cases increased. Demographics and risk factors

reported in West Virginia include month of death, county of residence, age at death, sex of child, distribution of death by race, position of baby when found, smoking status of mother, prenatal care information, co-sleeping information, prematurity, low-birth weight, breast-feeding and soft bedding. Research shows that breast feeding and firm bedding can be effective preventive measures in reducing SIDS.

The following chart shows the rate of SIDS in West Virginia over the past ten years, compared to the most recent national rates.



#### *Capacity to Address Needs:*

The Office of Maternal, Child and Family Health's Division of Research, Evaluation and Planning's Children's Reportable Disease Program housing the SIDS Project is an ongoing participant in the national *Back to Sleep* campaign and in disseminating information about other risk factors such as co-sleeping, maternal smoking during pregnancy, etc. The OMCFH makes every effort to provide relevant educational material to health care providers as well as parents, grandparents and care givers of West Virginia's newborns through community education and awareness. The SIDS Project Coordinator as well as the OMCFH Office Director are active participants on the Child Fatality Review team.

During SIDS awareness month, the SIDS Project provides infant blankets and packets of educational grief information to all West Virginia hospital emergency rooms. These packets of information are given to parents in the event of a sudden infant death. Informational packets on the *Back to Sleep* campaign are also sent to all newborn nurseries in WV to be shared with new parents.

## **BIRTH DEFECTS**

The West Virginia Birth Defects Surveillance System was established in 1989 to monitor the occurrence of birth defects among the state's children. In order to keep pace with growing health concerns, it was time to expand the capacity of the existing system. In September 2003, we were able to transition to an active case ascertainment surveillance system supported with CDC grant money. The purpose of the program is to maintain an effective early identification system, use information to enrich the quality of life of those affected by special conditions, provide public education awareness of prevention and create epidemiological studies using the collected data.

Original legislation was passed in 1982 (West Virginia State Code § 16-5-12a) mandating reporting of infants and minors up to the age of six identified with a birth defect. Additional revised legislation was passed in 2003 (West Virginia State Code § 64-81-1) to enhance the mechanism in place for timeliness of reports, assurance of confidentiality and verifying reportable diagnostic codes.

Previous to the implementation of an active case ascertainment system, West Virginia's weakness with birth defects surveillance was the under-reporting of birth defects from birthing facilities. Memorandums of Understanding with thirty-six West Virginia birthing facilities and three out of state birthing facilities were initiated to maintain a monthly reporting process for any infant born with a congenital anomaly.

In 2003, 729 total charts were reviewed through the combined efforts of a passive and active surveillance system. Of those 729 entries, 207 charts were actively abstracted from hospitals, while the remaining information was obtained from Vital Statistics' birth and death information.

During 2004 the Birth Defects Surveillance Program conducted 3,093 chart reviews based on individual hospital reporting of the discharge diagnostic codes. This included all major and minor congenital anomalies, slow fetal growth and fetal malnutrition, disorders relating to short gestation and low birth weight disorders related to long gestation and high birth weight, and 1,780 infants with diagnoses involving slow fetal growth, short gestation, long gestation, low birth weight and high birth weight were identified and reviewed in order to obtain a detailed look at possible risk indicators. The number of infants the program was able to obtain information on and make necessary referrals for, almost tripled each year since 2002.

Each infant identified through the surveillance system process is notified of Office of Maternal, Child and Family Health services through an informational mailing describing available programs. A report is generated quarterly detailing the number of infants who were referred from the Birth Defects Surveillance System to the CSHCN Program. Collaborative efforts between the Children with Special Health Care Needs



Program and Birth Defects Surveillance System will continue to assure the quality and effectiveness of linkages and services.

*Capacity to Address Needs:*

The Office of Vital Statistics has expanded its' surveillance methodology for electronic submission of birth certificates to 95%. This process has been effective given that an electronic birth certificate triggers a reporting form when the required box is marked indicating a birth defect. This process is continuously monitored by the Office of Vital Statistics to assure that necessary hospital personnel are familiar with the electronic submission process, given the frequent staff turnover in these facilities. Scheduled maintenance checks are in place with established key personnel to ensure current equipment meets the requirements for electronic submission. This is managed through a partnership with the Office of Epidemiology and Health Promotion, Office of Vital Statistics and the OMCFH.

In February 2005, the Birth Defects Surveillance Program was notified that it would not receive funding for additional years. Due to the loss of funding, the Birth Defects Surveillance Program has had to curtail the active abstraction process. Procedural changes were developed in order to meet the state requirements for the Birth Defects Registry. A reporting system continues in place; however the active review of charts will not occur. Hospitals continue to submit a monthly report of infants identified with a congenital anomaly and this information is matched with the Vital Statistics birth certificate and infant death records to obtain additional information. Information on available services for the infant and family continue to be mailed as well as referrals to CSHCN.

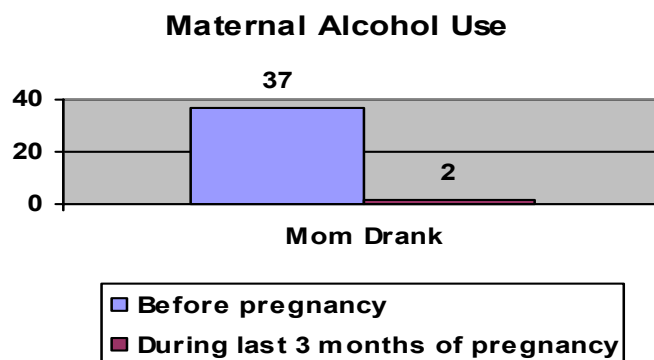
**SUBSTANCE ABUSE, TOBACCO CESSATION, SMOKING DURING PREGNANCY, AND SECOND HAND SMOKE EXPOSURE**

Most statistics rank WV lower than the US average on rates of alcohol use and other illicit drugs by pregnant women. Since data must rely on self report and there is no current means to accurately determine the rate of infants born with fetal alcohol syndrome, fetal alcohol effect and other drug effect, it is felt that these rates are underestimated. Between 1998 and 2002, there were 23 newborns reported in the Birth Defects Surveillance system as "fetus or newborn affected by maternal alcohol use". In small, rural WV hospitals, obstetricians and pediatricians have expressed concern about this issue because their community facilities are not prepared to treat drug addicted infants. Often there is no disclosure of the prenatal substance abuse and it is discovered only when the infant has signs and symptoms of withdrawal. This creates a serious dilemma for unprepared birthing facilities.

See the following chart for mother's alcohol use before and during pregnancy.

**Did mom have any alcoholic drinks during the 3 months before she got pregnant?**

**Did mom have any alcoholic drinks during the last 3 months of her pregnancy?**



WV PRAMS DATA 2002

Smoking during pregnancy has declined in the United States in response to public education and public health campaigns. Neonatal health-care costs attributable to maternal smoking in the United States have been estimated at \$366 million per year. Smoking-cessation programs remain a crucial strategy for preventing poor birth outcomes and decreasing the social and financial costs of smoking during pregnancy.

Cigarette smoking during pregnancy adversely affects the health of both mother and child. The risk for adverse maternal conditions (e.g., premature rupture of membranes, abruptio placenta, and placenta previa) and poor pregnancy outcomes (e.g., neonatal mortality and stillbirth, preterm delivery, and sudden infant death syndrome) is increased by maternal smoking. Infants born to mothers who smoke weigh less than other infants, and low birth weight (<2,500 grams) is a key predictor for infant mortality.

Women who quit smoking before or during pregnancy can substantially reduce or eliminate risks to themselves and their infants. The National Partnership to Help Pregnant Smokers Quit includes CDC and approximately 60 other organizations, working to ensure that health-care providers assess smoking status before, during, and after pregnancy and provide best-practice counseling on smoking cessation. Evidence suggests that specific cessation programs have been at least partly successful. However, not all women have responded to this public health message. Further efforts are needed to educate women of the health risks posed to their infants and themselves from smoking during pregnancy.

Although several states reported data that showed significant decreases in the rate of pregnant smokers, some as high as 76.1% (District of Columbia) from 1990-2002, the rate in WV only dropped from 27.8% to 26.2%, a 5.8% decrease. In 2002, smoking during pregnancy was reported by 11.4% of all women giving birth in the United States, a decrease of 38% from 1990, when 18.4% reported smoking. (CDC MMWR, October 2004).

Over one-fourth (26.2%) of the 20,986 births in 2003 were to mothers who smoked during their pregnancies, while 0.3% of births were to women who used alcohol. National figures show that 11.0% of women giving birth reported smoking during pregnancy and 0.8% used alcohol. Of the WV mothers who reported smoking during pregnancy, 13.3% of the babies born were low birth weight, compared to 7.0% for non-smoking mothers. US statistics show for 2002, 12.2% births to smoking mothers were low birth weight and 7.5% for non-smoking mothers.

**MATERNAL SMOKING RATES AMONG MEDICAID AND NON-MEDICAID  
SINGLETON BIRTHS: WEST VIRGINIA 2003**

<b>WEST VIRGINIA BIRTHS</b>	<b>MEDICAID BIRTHS N = 9075</b>	<b>MEDICAID MATERNAL SMOKING N (%)</b>	<b>NON MEDICAID BIRTHS N =8586</b>	<b>NON MEDICAID MATERNAL SMOKING N (%)</b>	<b>ALL PREGNANT WOMEN</b>
<b>TOTALS</b>	9075	4172 (46%)	8586	1454 (17%)	32%

Source: WV Birth Score Developmental Risk Screen and Newborn Hearing Screen Program: 2003 Birth Score Data Set matched to WV 2003 Vital Records.

Exposure to 2<sup>nd</sup> hand smoking (environmental tobacco smoke), is a risk factor for lung cancer in adults and for non-malignant lung disease in adults and children. It has also been linked to respiratory symptoms, reduced lung growth, irritation of the mucous membranes of the eyes, and upper airways.

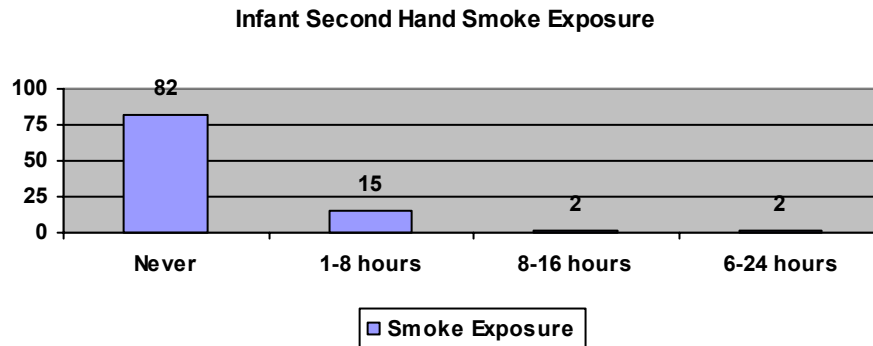
Epidemiological investigations conducted throughout the world have linked second hand smoke exposure by infants and young children to increased occurrence of respiratory tract illnesses, such as bronchitis and pneumonia.

West Virginia has been using tobacco settlement monies and Medicaid fee for service resources to target pregnant women for smoking cessation and discussions about second hand smoke.

In addition to schools and child care centers, children frequent restaurants, sport facilities, shopping malls, etc. Restrictions on smoking in restaurants have been controversial in West Virginia, with 23 of 55 counties enforcing bans.

See the following chart for second hand smoke exposure.

**About how many hours a day, on average, is your new baby in the same room with someone who is smoking?**



WV PRAMS 2002 Data

After the prenatal period, health care providers have the responsibility and opportunity to counsel patients on the dangers posed to children by exposure to ETS/second hand smoke. The recommended series of 12 well-child visits during the first six years of life can provide the occasion for pediatricians, nurse practitioners, and others not only to warn of the dangers of ETS, but also to inquire into the smoking habits of parents and other adults who come in contact with young children and to suggest strategies to reduce exposure. Similar opportunities exist for dentists who see children regularly for preventive care.

West Virginia network of pediatric specialists who interface on regular basis with medical practices offering EPSDT, encourage physicians to offer counseling about smoking cessation.

#### *Capacity to Address Needs:*

The RFTS Project received a grant from the WV March of Dimes in 2004 allowing the purchase of videos and standardized curriculum for use in participants' homes providing education on the dangerous effects of alcohol and other drugs during pregnancy.

Due to WV ranking number one in the United States for smoking during pregnancy, the RFTS Project implemented the WV RFTS 'SCRIPT' (Smoking Cessation Reduction In Pregnancy Treatment) as statewide protocol in October 2003.

The WV RFTS 'SCRIPT' used grant funding provided to the OMC FH from tobacco settlement dollars to purchase Carbon Monoxide Monitors for RFTS practitioners to use in participants' homes. Standard program protocol requires all Designated Care Coordinators (DCCs) (licensed social worker or nurses) to analyze the smoking status of every pregnant participant and offer best practice methods for cessation and/or reduction. The CO monitors have proven to be a valuable tool allowing women to visualize the results of their cessation/reduction efforts immediately. A recent incident in rural WV proved the value of the CO monitor when the level was noted to be 89 parts per million (ppm) for a pregnant smoker who was sixteen weeks pregnant. The level which suggests the presence of Carbon Monoxide is as low as 4ppm. Therefore, the level of 89 was critical and, after brief investigation, the family vacated the home after discovery of a Carbon Monoxide leak. Since the RFTS Designated Care Coordinator was following Project protocol for CO monitoring, the lives of this family were saved from serious health consequences or death.

Data included in the 2003 RFTS Annual Report suggests that fewer RFTS families allow their infants to be exposed to second hand cigarette smoke. The 2003 RFTS Project data correlates with the 2003 Pregnancy Risk Assessment Monitoring System (PRAMS) data indicating that more WV families are protecting their children from exposure to environmental tobacco smoke.

THE WEST VIRGINIA RIGHT FROM THE START 'SCRIPT' (Smoking Cessation/Reduction in Pregnancy Treatment) Initial Data July 1, 2002 to December 31, 2002						
AGE	# REPORTED SMOKERS	% TOTAL SMOKERS	# REPORTED QUITTERS	% TOTAL QUITTERS	# REPORTED DECREASED	% TOTAL DECREASED
<18 years	198	10	7	10	19	13
18-25 years	1,289	68	56	80	92	63
26-35 years	350	18	7	10	32	22
36-42 years	61	3	0	0	4	2
> 43 years	2	<1	0	0	0	0
TOTALS	1,900	20	70	4	147	8

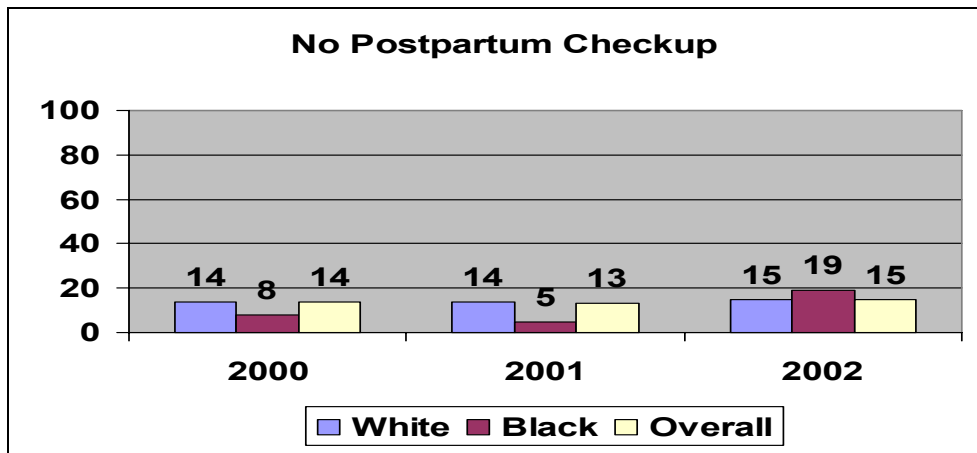
## **MENTAL HEALTH ISSUES**

CDC Pregnancy Risk Assessment Monitoring Survey (PRAMS) data published in June 2004 in the article "Spotlight on Safe Motherhood" details the responses of 453,186 women who gave birth to a live infant in seven states in 2000. Overall, 7.1% (32,176) reported severe depression after delivery and more than half (233,844) reported low to moderate depression. Women with fewer than 12 years of education, those who were Medicaid recipients, and those who delivered low-birth-weight babies were most likely to report severe depression. In addition, women who experienced

physical abuse during pregnancy and women who reported emotional, partner-related, financial, or traumatic stress were more likely than other women to report being severely depressed. In addition to directly influencing the emotional wellbeing of mothers, postpartum depression (PPD) has been shown to affect marital relationships, mother–infant bonding, and infant behavior.

Depression among mothers in the months after delivery has surfaced as an important maternal and child health concern. According to the March Of Dimes, health care providers should speak with their patients about PPD during prenatal care and well-baby visits, because more than half of new mothers reported being depressed. Pregnant women should be educated about PPD during the third trimester, and obstetricians/gynecologists should consult with their patients about their risk for psychiatric illness during the postpartum period.

**Since your new baby was born, have you had a postpartum checkup for yourself?  
Percent responding “No”**



WV PRAMS 2002 Data

#### *Capacity to Address Needs:*

Since WV’s population includes a large number of pregnant women who are low-income, medically indigent, uninsured/underinsured, have less than a high school education, lack transportation, lack resources, experience domestic violence, and use harmful substances, it is evident that these women are at risk for postpartum depression. The WV RFTS Project screens all pregnant women for depression at or near the time of delivery and then again prior to sixty days postpartum. The Project has clear guidelines for referral criteria depending on the score obtained on the depression screening tool.

The WV RFTS Project partners with the WV Healthy Start HAPI (Helping Appalachian Parents and Infants) to address mental health issues including postpartum

depression. The HAPI Project uses the already existing network of RFTS DCCs to assess needs and deliver services to at risk women and infants in 4 WV counties following discharge from the RFTS Project at sixty days postpartum. Included in the services provided through the HAPI Project are assessment, referral, and funding for the treatment of postpartum depression.

The RFTS and HAPI Projects were recognized at the 2003 National Healthy Start Annual Conference and asked to provide an oral presentation for the general session. The two Project directors presented a joint power point presentation on the collaborative efforts between the WV Office of Maternal, Child and Family Health and the HAPI Project and received positive feedback from conference planners and attendees.

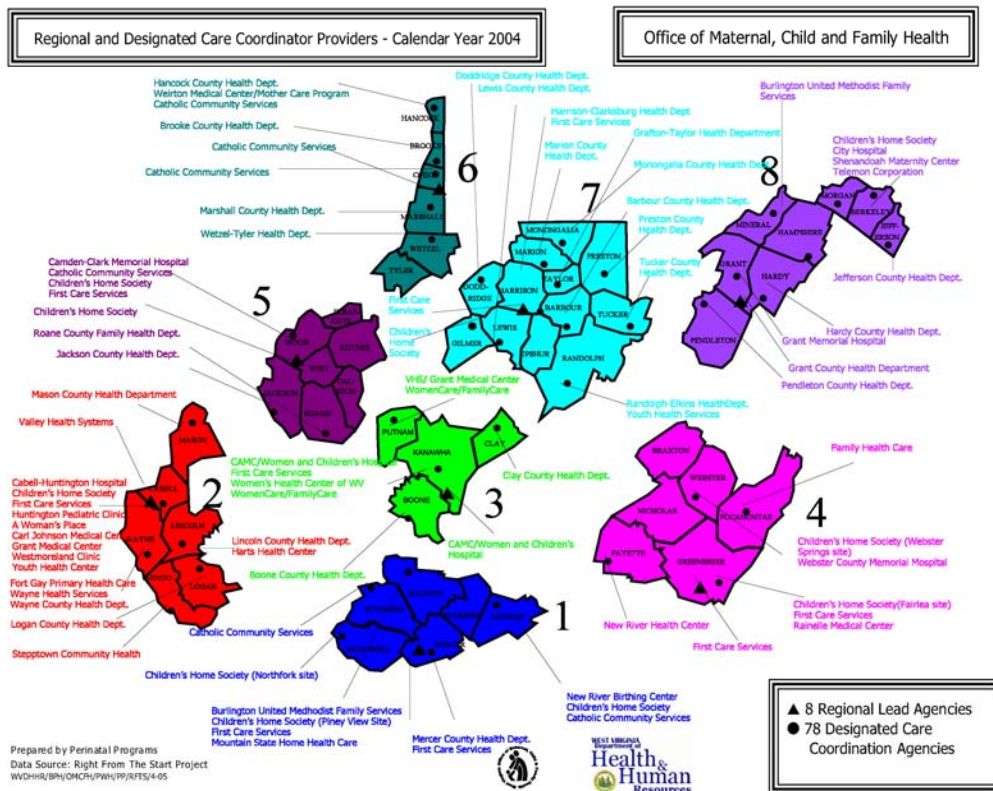
## **DOMESTIC VIOLENCE**

According to the West Virginia Uniform Crime Report, West Virginia State Police, an average of two domestic homicides occurred in West Virginia each month. This average has held steady since the late 70's. Law enforcement agencies reported a total of 10,397 complaints of domestic violence in 1998, a 4.1% increase over the 1997 figure.

According to the Justice Statistical Analysis Center, Dept. of Military Affairs and Public Safety, report that since 1989, domestic violence complaints to law enforcement agencies have increased by 400%. Between 1990 and 1997, the number of domestic violence petitions processed by magistrate courts tripled. Statistics prove that domestic violence is often more common during pregnancy and that the perpetrator is most often the significant other or spouse.

### *Capacity to Address Needs:*

The 280+ RFTS Project Designated Care Coordinators, (DCC), registered nurses and licensed social workers, are trained in and experienced with recognizing signs and symptoms of domestic violence among pregnant women. They also recognize that spousal domestic violence is more prevalent during the time that a couple experiences pregnancy. All DCCs are trained on how to interview women in a safe environment and how to refer them to the appropriate intervention sources when necessary. In Fiscal Year 2003-2004 licensed domestic violence programs directly served 18,579 West Virginians. (WVCADV Annual Report FY 2003-2004). RFTS DCCs are knowledgeable of the resources which are available to families within their own communities and routinely utilize them as referral and support services for Project participants. A map of the community based network follows:



## **PERINATAL (RFTS) INFRASTRUCTURE**

According to the RFTS 2003 Annual Report, the RFTS Project provided services to 52% of Medicaid/Title V eligible pregnant women and 27% of eligible infants. The reasons that more eligible clients did not receive services are as follows: the Project did not receive the client referral; the client refused to accept services; or the DCC was unable to establish contact with the client following receipt of the referral.

Although there are many entities in WV who refer at risk families to the RFTS Project on a regular basis, many others do not. There have been three infant deaths recently in WV which could have possibly been prevented had the family been receiving services from RFTS.

All pregnant women who are low income and medically indigent, with incomes under 185% Federal Poverty Level (FPL) are eligible to receive RFTS services. There are many other families who need the education, support, and care coordination offered by the Project. As women delay childbearing to pursue their careers, they often experience fear of the inability to acquire adequate parenting skills as older first time mothers.

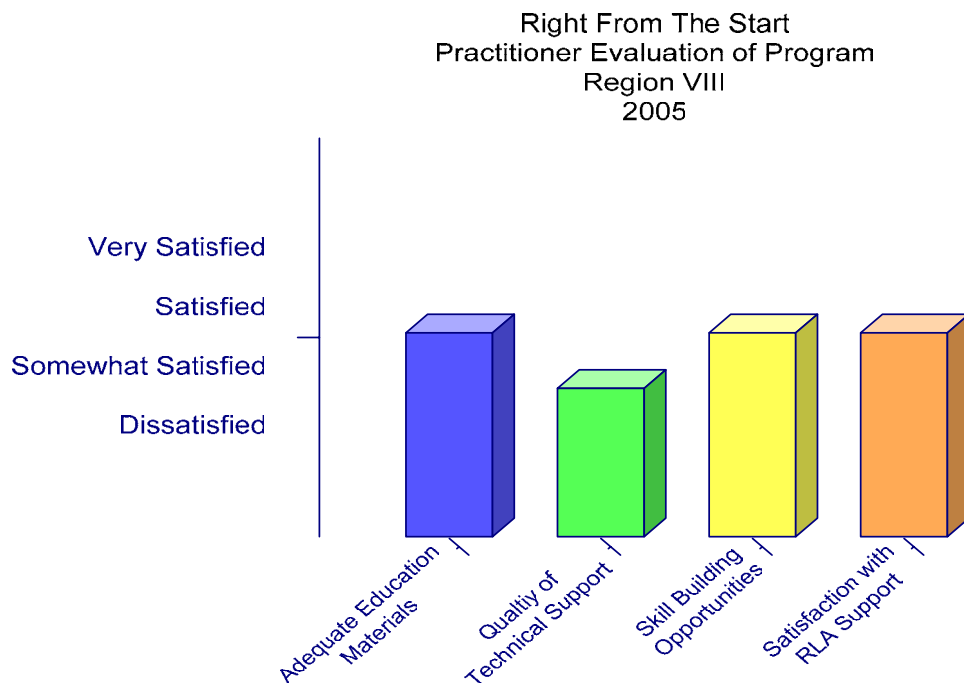


Finally, the problem with provider reimbursement in West Virginia is very serious. The RFTS Project provider network has not received an increase in the reimbursement rate for Medicaid eligible patients since the inception of the Project. Because the cost to provide prenatal and infant care has skyrocketed in the last ten years, providers are experiencing difficulty in maintaining their practices due to poor reimbursement for medical services rendered to patients. Therefore, many providers have decided to no longer provide prenatal care for those patients who qualify for Medicaid coverage. Even though access to 1<sup>st</sup> trimester prenatal care for WV women has improved in the last ten years and pregnant women are now healthier, the improvements will begin to decline and poor birth outcomes may be experienced unless there is an increase for provider reimbursement.

*Capacity to Address Needs:*

Because of the unique relationship established between the pregnant woman and the DCC, there is often disclosure of needs and pleas for assistance. All DCCs are trained on how to interview women and determine what referrals would meet those needs. RFTS DCCs are knowledgeable of the programs within their own communities and routinely utilize them as referral and support services for Project participants.

The RFTS Project has approximately 84 community agencies throughout West Virginia who have contracted with the OMCFH to provide care coordination and enhanced education services to high risk pregnant women and infants. The 280+ DCC providers are dedicated to the core public health function of assisting these populations with access to early and adequate prenatal/health care. Besides these providers, there are many obstetricians, nurse practitioners, nurse midwives, and family practice physicians in WV and WV's bordering states that are contracted with the OMCFH RFTS Project to provide quality obstetrical and delivery care to pregnant women in WV according to ACOG national standards. This trained network of providers has provided quality, best practice services to eligible WV families since 1989 and continue to do so today even though reimbursement for services is inadequate. Thus the network to provide quality care to pregnant women and infants up to age one year exists statewide and has proven effective as seen in the data which shows a rate of access to 1<sup>st</sup> trimester prenatal care in WV of 86%.



## **DATA COLLECTION AND ANALYSIS**

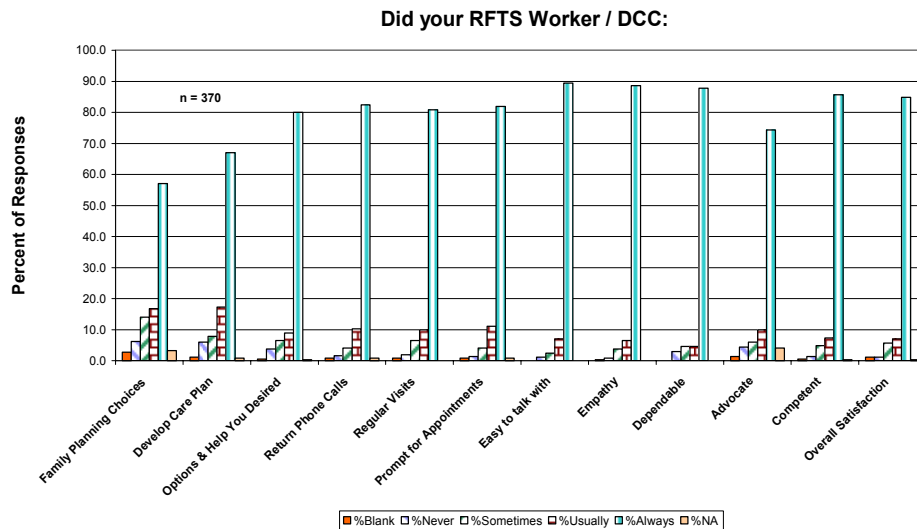
Other states have recognized that West Virginia's perinatal project (RFTS) is unique, providing needed services to WV families and have expressed interest in using the Project as a model to implement similar programs in their states. The RFTS Project was featured as a presentation at a general session of the National Healthy Start Conference in Washington, DC in September 2003. AWHONN (Association of Women's Health, Obstetricians and Neonatal Nurses) has asked the RFTS Project to provide a poster presentation at the national conference in Salt Lake City, Utah in June 2005.

The Project collects valuable data on numerous aspects of perinatal care for the high risk prenatal and infant population in WV. The Project produced a large amount of data for the Year 2003 and has stored the data on CD in an informative, provider friendly, clearly presented, printable report. This report and maintenance of important data is a joint effort of the OMC FH Research and Perinatal Services units and will be replicated on an annual basis.

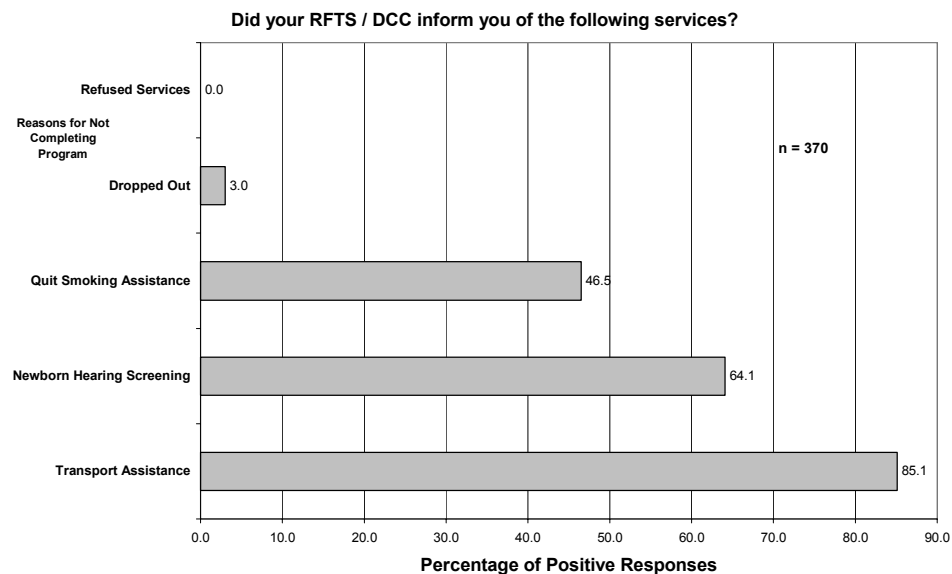
In 2003, the RFTS Project initiated the use of a Client Satisfaction Survey which continues to be mailed out to all Project participants statewide by the Regional Lead Agencies at case closure. The survey asks the client: if they received information on smoking cessation; transportation assistance; newborn hearing screening; whether or not the client's needs were met; if the client was allowed to have input into the

development of the Service Care Plan; and satisfaction with services received as well as numerous other issues. The data is stored within a database at the OMCFH and is analyzed on a regular basis. The survey provides valuable information which enables the Project to make improvements in service delivery to WV families. The survey also enables the Project to identify and correct provider noncompliance issues. This provides additional quality assurance oversight and allows the Project to act as a “gatekeeper” of the resources which are dedicated to the RFTS Project and intended for client services.

### Right From The Start-Client Satisfaction Survey 2004



### Right From The Start-Client Satisfaction Survey 2004



### *Capacity to Address Needs:*

#### Division of Research, Evaluation and Planning

This Division is responsible for the epidemiological and other research activities of the Office of Maternal, Child and Family Health, including all programmatic data generation and program/project evaluation endeavors, as well as ensuring that the Office of Maternal, Child and Family Health's planning efforts are data-driven. All of the Office of Maternal, Child and Family Health's program specific data personnel are housed in this Division, and are linked with program leadership to assure consistent visioning. There are three (3) epidemiologists who cover PRAMS, Breast and Cervical Cancer Screening, Childhood Lead Poisoning Prevention, SIDS, Birth Defects and Newborn Metabolic Screening. These epidemiologists submit all data reports and snapshots for their assigned programs as well as submit the grant applications where applicable.

Within the OMCFH, the Research, Evaluation and Planning Division houses the Data Management and Data Entry Units. There are currently six (6) programmers with varying levels of expertise, knowledge and skills that has allowed the development of new databases, along with the restructuring of old and linking and matching data between the program databases to enhance informational capacity. One of the programmers is designated as the Web designer and has designed the Web sites for OMCFH programs. One of the six (6) programmers is also dedicated to the RFTS Project. The Bureau for Medical Services (Medicaid) understands the need for having data collection capacity and shares the cost of the RFTS programmer. Each Regional Lead Agency is responsible for its own data entry. The programmer offers support to all eight Regional Lead Agencies and problem solves with the staff on electronic programs and equipment needs.

Following is a list of partners that collaborate with RFTS.

**RFTS Collaborative Partners**

WV March of Dimes
Healthy Mothers, Healthy Babies
WV Health Check
WV CHIP
WV Hospital Association
WVU Healthy Start/HAPI Project
WVU Birthscore Office
WV ACOG (American College of Obstetricians and Gynecologists)
Dr. Richard Windsor, George Washington University (SCRIPT)
State Legislature
National Partnership to Help Pregnant Smokers Quit
Nurse/Family Partnership
WV DHHR offices
WV Local Health Departments
Norman Montalto, DO, Charleston Family Practice (Support for Smoking Cessation)
WV Birth to Three
WV OMCFH Children's Special Health Care Needs
WV Audiologists
AWHONN
WV Family Planning
Family Resource Networks
Parents As Teachers
Children's Protective Services
Charleston Area Medical Center
All WV birthing facilities
Channing Bete
Valley Health Systems
First Care Services
Children's Home Society
Catholic Community Services
Bedfont Scientific
Kentucky Voices of Appalachia
Public Employees Insurance Agency (PEIA)
WV Committee Against Domestic Violence
WV Office of Epidemiology and Health Promotion
WV WIC
WV Office of Community Health Systems
Relatives as Parents Program

## **FAMILY PLANNING**

The Family Planning Program needs assessment for FY 2005-2006 consists of a broad analysis of statewide birth, fertility, behavioral and service data for women and teens at risk of unintended pregnancy. A description of high priority populations and existing resources is provided. The need for family planning services and the extent to which that need is being met by the Family Planning Program was evaluated.

### **Family Planning Program Utilization:**

Any female or male capable of becoming pregnant or causing pregnancy whose income is at or below 250% federal poverty level is income eligible to receive free or low-cost clinical examinations and free contraceptives through the WV Family Planning Program. Federal Title X regulations require clinics to provide confidential services to everyone regardless of their age, including minors seeking contraception.

Circumstances which may contribute to eligibility include employment at an entry-level, temporary, minimum-wage or low-wage job; unemployment; enrollment in school or college; inability to afford monthly birth control supplies; inadequate or no health insurance coverage for contraception; having non-managed care Medicaid; or no longer eligible for WV WORKS (TANF) benefits or Medicaid. Of the 63,658 clients receiving services, 55,710 (or 87.5%) had incomes less than 100% of the federal poverty level.

The Family Planning Program (Title X/Title V/State Funds) targets services toward the following populations: low-income, uninsured women; sexually active teens or teens contemplating sexual activity; males; Medicaid-eligible clients (non Medicaid HMO); and individuals receiving Temporary Assistance for Needy Families (TANF).

As documented on the federal Family Planning Annual Report (FPAR), in CY2004, the Family Planning Program provided clinical services to 63,658 unduplicated women, men and adolescents, a decline of approximately 0.8%.

Confidential access to contraceptive services is crucial in helping sexually active teenagers obtain timely medical advice and appropriate medical care to reduce teen pregnancy and STD rates. In CY2004, the Family Planning Program provided confidential contraceptive services to 17,957 teens (17,383 females and 574 males).

### ***Capacity to Address Needs:***

In addition to Family Planning Program and Medicaid Program coverage for contraceptive services and reproductive health care, the West Virginia Children's Health Insurance Program (CHIP Phase II) is yet another resource to assist with financial coverage for care provided to children ages 6 to 19 years with family income between 100% - 150% FPL. Implemented in early 1999, West Virginia CHIP Phase II is administered by the Public Employees Insurance Agency (PEIA) and pays for services

provided by WV health care providers. Phase II is a fee-for-service (vs. managed care) plan. There is no charge to the family for any services included in the plan - no premiums, deductibles, or co-payments. Health care providers are reimbursed at the prevailing PEIA rate for CHIP Phase II services.

CHIP Phase II provides excellent coverage for family planning office visits, annual Pap smears, general labs (STD screening services), and prescription drug benefits, which cover oral contraceptives and estrogens/progestins (Depo-Provera injections). The only identified drawback to CHIP Phase II is the inability of providers to offer confidential family planning services for sexually active adolescents, as this is permissible only by Title X regulation or State law (which WV does not have).

### **Unintended Pregnancy/Teen Pregnancy**

Following are some brief data facts from the WV Health Statistics Center:

#### **Live Births:**

West Virginia resident live births increased by 261, from 20,725 in 2002 to 20,986 in 2003. The 2003 birth rate of 11.6 per 1,000 population also rose from 11.5 in 2002. The U.S. 2003 birth rate was 14.1 live births per 1,000 population, higher than 2002 (13.9). West Virginia's birth rate has been below the national rate since 1980. It has continued its overall decline, interrupted by slight upturns in 1989 through 1991, 1999 and 2002, and 2003.

#### **Fertility:**

The 2003 U.S. fertility rate of 66.1 live births per 1,000 women aged 15-44 was 2.0% higher than the 2002 rate (64.8). West Virginia's fertility rate, also, increased .9% from 55.6 in 2002 to 56.1 in 2003. The fertility rate among women aged 15-19 in West Virginia was 0.2% lower than that among young women in the U.S. (41.6 vs. 41.7). The fertility rate among women aged 20-44, however, was also lower (16.7%) in the state than in the nation (58.7 vs. 70.5).

#### **Teen Births:**

The number of births to teenage mothers decreased by 70 (2.6%), from 2,646 in 2002 to 2,526 in 2003. The percentage of total births represented by teenage births decreased from 12.8% in 2002 to 12.3% in 2003. The significantly lower fertility rate among older women, however, resulted in teenage births continuing to constitute a higher proportion of total births than is found nationally (10.3% in 2003).

The decline in teen birthrates in the early 1990's was largely due to declines in repeat teen births, whereas the declines in the latter part of the decade were attributed to declines in first teen births. In 2002, one in five births to teens were second or higher order births, and nearly one fourth of teen mothers have a second birth before turning 20. An earlier Child Trends study revealed that 19% of all WV teen births in 2000 were

repeat births, indicating a continued need for enhanced contraceptive education for teen mothers.

#### Out-of-Wedlock Births:

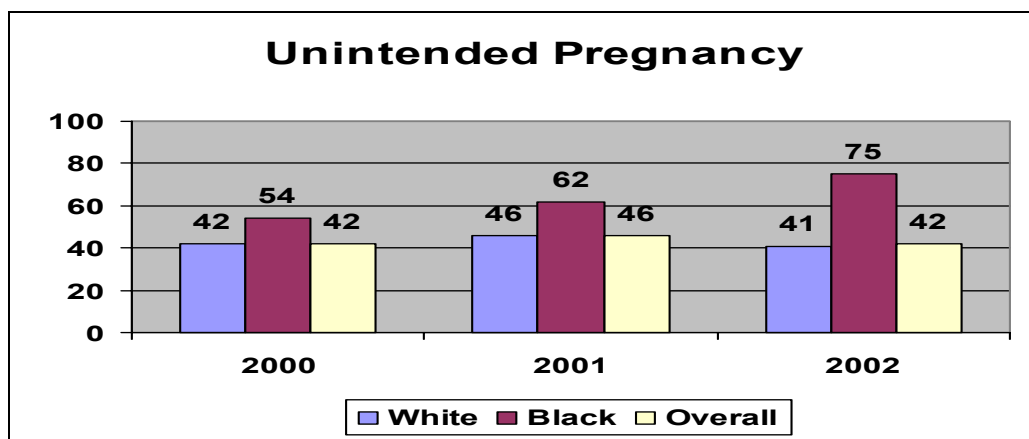
The percentage of births occurring out-of-wedlock rose from 2002. In 2003, over one out of every three (4.4%) West Virginia resident births were to an unwed mother. The percentage of white and black births that occurred out-of-wedlock in West Virginia in 2003 were 33.1% and 75.4%, respectively, compared to 31.6% and 72.1% in 2002. The percentage of teenage births to unmarried teenage mothers in the state noticeably increased from 71.4% in 2002 to 76.1% in 2003.

As the median age of first marriage continues to rise (in 2003 half of women were married by age 26.0), the likelihood of teens having a birth within marriage declines. Currently, 80% of teen births occur outside of marriage.

When comparing out-of-wedlock births to teens ages 10-19 to those to adults ages 20-44, it is clear that adult women comprise the majority of births to unmarried women, a statistic that is increasing over time. The percentage of out-of-wedlock births to teens is gradually declining. The Family Planning Program consistently serves a large number of women with contraceptive care, but does not have a true capacity to impact marital status when a pregnancy is confirmed. Prevention of teen pregnancy and unintended pregnancy in women of all ages remains the focus of the WV Family Planning Program.

In 2002, of women living in West Virginia and delivering a live infant 58.3% were intended pregnancies and 41.7% were unintended. This represents a decrease in the number of unintended pregnancies.

**Thinking back to just before you got pregnant, how did you feel about becoming pregnant?** (intended includes sooner or then and unintended includes later or not at all)



**Percent responding to unintended**

PRAMS Data Source



Despite a decline in teen pregnancy during the 1990's, unintended pregnancy still poses a major problem for adolescent females in West Virginia. The vast majority (85%) of pregnancies among teens are not fully planned or intended. Rather, they result from accidents or teens ambivalence about pregnancy, their confusion about preventing it, and sometimes their failure to make any clear decisions about abstinence, sexual activity, or contraception. Early sexual activity is strongly associated with unintended pregnancy and sexually transmitted diseases.

While welfare reform efforts have focused on reducing expenditures on families begun by teens, less attention has centered on how to prevent teen pregnancy, and thus reduce the need for such services in the first place. The Southern Regional Project on Infant Mortality documented that for every one dollar (\$1.00) West Virginia expended to support families begun by teens, it spent only one cent (\$.01) on investments to prevent teen pregnancy. On a national level, taxpayers pay a high price for teen childbearing. A recent study found that teen childbearing costs taxpayers \$6.9 billion each year or \$2,831 per year per teen mother.

There are multiple compelling reasons to provide financial support for adolescent pregnancy prevention activities:

#### Teen Pregnancy Data:

- Among teenagers, approximately 85% of pregnancies are unintended.
- Half of all initial adolescent pregnancies occur within the first 6 months following first intercourse and 20% occur within the first month.
- 28,360 West Virginia adolescents are in need of publicly supported contraceptive services.
- It is estimated that nearly 11,000 West Virginia female teens between the ages of 12-19 are at risk of unintended pregnancy, but are not currently receiving family planning services.
- The percentage of births occurring out of wedlock rose from 2002, and one out of every three (34.4%) West Virginia resident births in 2002 were to unwed mothers.
- Births to unmarried teens in the state noticeably increased from 71.4% in 2002 to 76.1% in 2003.
- West Virginia teen pregnancy rate ranks 35<sup>th</sup> in the nation. Of the estimated 4,050 teen pregnancies each year, 70% result in live births, 15% result in miscarriages, and 15% result in abortions.
- Age of youngest mother in 2003, 12 years.

#### Teen Population Data:

- By 2010, the number of girls age 15-19 is projected to increase by 2.2 million nationwide.
- Only 25% of adolescent mothers graduate from high school.
- Four in ten girls get pregnant at least once before age 20.

- There is a strong association between a mother's age at first birth, poverty, and later receipt of public assistance.
- Children born to adolescents are far more likely than other babies to be born with very low birth weights, to have learning disabilities, have to repeat a grade in school and to suffer child abuse and neglect.
- Girls of adolescent mothers are more likely to become adolescent mothers themselves and boys of adolescent mothers are more likely to become incarcerated.
- Teenage parents are at especially high risk of long-term welfare dependence. Recent research indicated that nearly half of all teenage mothers go on welfare within five (5) years after becoming a parent. Most went on and off welfare more than once, spending an average of eight (8) to ten (10) years receiving public assistance over their lifetimes. Even though teenage parents made up only a small proportion of welfare recipients at any given time, nearly half of all welfare recipients were single women who had given birth as teenagers.

Comprehensive sex education can help delay sexual activity and give students the tools to avoid unintended pregnancy and STDs when they do become sexually active. Research conducted by Douglas Kirby for the National Campaign to Prevent Teen Pregnancy shows that programs that provide teenagers with comprehensive sex education, including discussion of contraception in addition to abstinence, can be effective in helping teens to delay sexual activity, to use contraceptives when they do become sexually active, and to have fewer partners.

The Adolescent Pregnancy Prevention Initiative conducted anonymous surveys of students participating in classroom presentations in the 2003-2004 school year. The survey tool, provided by Advocates for Youth, assessed student opinions (grades 6-12) on school-based sexuality education. Highlights from 1,001 surveys were summarized as follows (results may not total 100% - this list includes only major responses):

- **When do you believe sex education should begin?**  
Middle/junior high school (60.04%)  
Before 6<sup>th</sup> grade (26.7%)
- **How would you rate sex education at your school?**  
So-So-Covered Anatomy (36.16%)  
Above Average – Covered most questions (23.88%)  
Terrific – Covered all (16.18%)
- **Are/were your teachers comfortable and knowledgeable?**  
Yes (56.14%)  
No (7.69%)  
Not Sure (36.16%)
- **Do you feel you received complete information and the pros/cons of abstinence and contraception?**  
Yes (49.65%)

- No (21.38%)
- Not Sure (28.97%)
- **Who do you think should be responsible for sex education?**  
Parents (42.78%), School (39.55%), Clubs/Organizations (7.37%), Church (5.33%), Not Sure (4.99%)
- **Where do you get most of your information about sexuality?**  
Peers (25.73%), School (22.29%), Parents (21.7%), Brothers/Sisters (8.86%), Media (8.65%)
- **How do you feel about schools' educating students only about abstinence and not about contraception and condoms?**  
Is Bad (60.34%), Not Sure (23.48%), Is OK (16.18%)

Survey results will be used to guide student discussions in future presentations.

The following results illustrate sexual behaviors that result in HIV infection, other sexually transmitted diseases (STDs), and unintended pregnancy, and that place WV youth at risk:

- In 2003, 52% of WV high school students reported they had engaged in sexual intercourse, a decrease of 1% from 2001, a total decrease of 11% from 1993.
- Of the 52% of West Virginia high school students reported having sexual intercourse, 7.3% reported sexual intercourse before age 13 and 16.5% reported sexual intercourse with more than 4 partners.
- There were 2,574 adolescent births in 2003 compared to 2,645 births in 2002, a decrease of 71 fewer births to adolescent mothers. (0.9% decrease)
- In an average week in West Virginia, 55 babies are born to mothers 15-19 years of age.
- In CY 2004, 17,383 adolescents aged 12-19 were served in Family Planning Program clinics.

According to YRBS data, 52% of all U.S. high school teenagers have had sexual intercourse at least once. Contrary to popular belief that teens are experiencing their first sexual intercourse during the after school hours, recent data from the National Longitudinal Survey of Youth, 2000, show that the most common time period that teens between the ages of 16 and 18 first have sex is at night (10pm to 7am), and the most common places are their family home or their partner's family home. Although health risk behaviors of teen sexual activity are improving, this data offers additional insight that may aid parents, teachers, community youth leaders, and others when considering and planning youth activities.

#### Contraceptive Use Among Teens:

The proportion of sexually experienced female teens that ever used a birth control method increased slightly between 1995 and 2002, from 96.2% to 97.7%. Use of the pill

increased from 51.6% to 61.4%, use of injectables increased from 9.7% to 20.7%, and about 8% of sexually experienced female teens had used emergency contraception.

Although contraception is an extremely important issue for sexually active teens to consider, less than two-thirds (59%) said they discussed the use of contraception with their partners before having sex for the first time.

In 2004, the Alan Guttmacher Institute (AGI) published a report, "Contraceptive Needs and Services, 2001-2002 Estimates" with estimates by state and county of the numbers of women needing contraceptive services and supplies, according to their age and income level. The report presented state and county level information on the availability of private physicians and publicly supported family planning clinics, and compared the level of clinic services with the number of women needing contraceptive care and supplies from publicly supported providers. These data provide geographically comparable information that is used to plan and monitor care.

The CY 2004 Family Planning Program Annual Need Met Report provides information on the percent of the need met for each county in West Virginia. With the exclusion of non-West Virginia residents, in CY 2004, 61,622 unduplicated women and teens with incomes less than 250% of the federal poverty level received subsidized services. This figure represents 58% of women (of the at-risk population of 106,240) needing contraceptive care and supplies had their need met in 2004. Of the 177,300 women in West Virginia at risk of unintended pregnancy, 106,240 – including 28,360 teens – are in need of publicly supported family planning services.

#### Emergency Contraceptives:

The U.S. Guide to Clinical Preventive Services identified post-coital administration of emergency contraceptive pills (ECP) after unprotected intercourse as a means of reducing subsequent pregnancy. ECP is estimated to reduce the number of subsequent pregnancies by 75 percent.

The following is Family Planning Program ECP Data for CY 2004:

- ECP Administration: 1,489 Visits
- ECP Follow-up: 139 Visits
- ECP Advance Prescription: 280 Visits
- 109 of 140 sites (77.9%) of all FP sites prescribed on-site. The remaining 31 sites (22.1%) referred FP clients to another site for administration.

#### Action Steps

- Distribute to the family planning provider network ACOG practice guidelines for emergency oral contraceptives.

- Establish as Family Planning Program protocol the expectation that all providers in the network (recipients of Title X/V) offer emergency contraception or establish formal linkages for dispensing by an alternate source.

#### *Capacity to Address Needs:*

Subsidized medical care is the only health resource for many West Virginia residents, in particular those seeking women's reproductive health care. The economic status of the State has dramatically influenced the availability of adequate health care for many families.

The Family Planning Program has established multiple partnerships and linkages with other State Government agencies, community-based organizations, health care providers, associations and other entities to promote coordination of resources for reproductive health care. Currently, the Family Planning Program maintains agreements with 140 community agencies (county health departments, primary care centers, private provider practices, and hospital outpatient centers) for clinical service delivery.

Many private practitioners (not participating in the Family Planning Program) provide contraceptive and basic reproductive health services for Medicaid clients or insured clients. It is difficult for these private practitioners to adequately serve low-income, uninsured clients however, due to the inability of clients to pay for the medical care and to purchase expensive contraceptive medications, supplies and devices from pharmacies. WV has only one (1) Planned Parenthood affiliate, Planned Parenthood of West Virginia, which does not participate in the Title X Family Planning Program.

#### **Adolescent Pregnancy Prevention Initiative**

As a focus area of the Family Planning Program, the goal of the Adolescent Pregnancy Prevention Initiative is to reduce the number of pregnancies among adolescents through improved decision-making skills, abstinence, and/or access to contraceptive services. The Adolescent Pregnancy Prevention Initiative (APPI) is comprised of (5) full-time employees: (1) Coordinator and (4) Adolescent Pregnancy Prevention Specialists, who conduct community education and outreach activities on a regional/local level. These (4) Adolescent Pregnancy Prevention Specialists work to increase public awareness of problems associated with early sexual activity and childbearing and collaborate with existing community organizations to promote local activities for adolescent pregnancy prevention. APPI offers abstinence-based education but includes information about contraceptives and access to family planning services.

Examples of activities completed by the Adolescent Pregnancy Prevention Specialists in 2004 included:

- Developed and conducted community education and outreach activities to promote public awareness of adolescent pregnancy prevention, negative consequences of early sexual activity and childbearing, and related issues. (8 presentations)
- Participated in community/county activities that impact the well-being of adolescents. (30 meetings/events, 2 health fair exhibits)
- Developed and conducted education/information workshops for parents of adolescents on improving parent/child communication skills.
- Conducted on-site visits to middle and high schools to provide information about APPI and offer technical assistance and resources. (67 school visits)
- Developed and presented pregnancy prevention information to students in middle and high school classrooms. (74 school presentations).
- Conducted a pilot project at Mt. View Middle School, McDowell County, using the “Wise Guys” program in fall 2004 semester. This project was very successful and will be repeated in spring 2005 for a group of young males and also a group of young females using “Wise Gals”, at the request of school administrators at Mt. View Middle School.
- Conducted 3 informal “Lunch and Learn” sessions at Cheat Lake Middle School at the request of the school administration to address the questions of the female students in spring 2004.
- Assisted Petersburg High School with a Social Studies project on teen pregnancy. The students used the “empathy belly” provided by APPI and measured students’ response to having a pregnant student in class with them. The project won at the county level and competed in the state competition. The students then presented their findings to the Petersburg student body.

#### *Capacity to Address Needs:*

APPI is currently funded by the Family Planning Program with \$250,000 from revenue generated from providing Family Planning services to West Virginia Medicaid clients. Since mid-2004, this Special Revenue source has decreased with gradual transition of West Virginia Medicaid clients to Managed Care. Family Planning providers now direct bill the HMOs, so Medicaid reimbursement (and thus Special Revenue funds) to the state Family Planning Program are disappearing. Continued financial commitment is needed to continue the progress of the Adolescent Pregnancy Prevention Initiative. A budget of \$250,000 is needed to support the (4) outreach Pregnancy Prevention Specialists currently serving all of West Virginia. The Family Planning Program will continue to seek funding from outside agencies and resources to help off-set the APPI budget, such as Title X, West Virginia Department of Education, WV Medicaid, and alternative public/private grants.

The following is a list of partners that collaborate with APPI:

**APPI Partnerships**

WV Board of Education
State School Board of Education National Healthy Schools network (team member)
Adolescent Health Initiative
Abstinence Education Project: WV Abstinence Only Education Advisory Council
WV School Based Health Assembly
National School Boards of Education, WV Team member;
WV School-Based Health Center network;
WV School Health Committee;
Coalition for WV Children
Region III Teen Pregnancy Prevention Leadership Group
WV DOE, Office of Student Services & Health Promotions, HIV/AIDS Program
County Family Resource Networks (55)
Harrison/Marion Tobacco Coalition
Preston County HAPI Consortium
GEAR-UP
Monongalia County Adolescent Pregnancy Prevention Task Force
PATCH of Marion County
Monongalia County After School for All
Communities of Shalom
Charleston Public Safety Council, Youth Task Force
Starting Points of Morgan County
Region VIII Adolescent Health Task Force
McDowell Rural Health Advisory Committee
Healthy Opportunities for Positive Education (HOPE), McDowell County
Improving Mentoring Positive Actions for Children and Teens (IMPACT), Greenbrier County
Child Abuse Prevention Education (CAPE), McDowell County
Healthy Communities Access Progress, McDowell County
Families, Agencies, Children's Enhancing Services (FACES), McDowell County
Creating Opportunities for Youth, Mercer County
Safe, Healthy, Active Positive Empowered and Drug Free (SHAPED), Raleigh County
Youth Enrichment Issues, Fayette County
Bright Beginnings, Wyoming County Opportunity Council
Parents Reading in School Monthly (PRISM), McDowell County
Greenbrier Connections Collaborative, Greenbrier, Summers and Monroe Counties
Summers/Monroe Wellness Committee

In addition to the APPI, WV OMCFH administers the Abstinence Project and the Adolescent Health Initiative through its Infant, Child and Adolescent Health Division.

## **Abstinence**

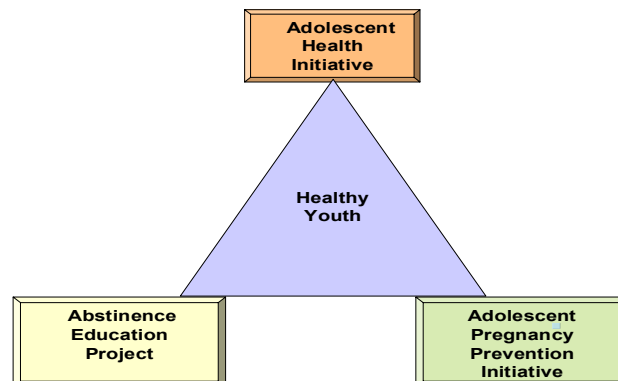
The West Virginia Abstinence Education Project is coordinated by the Infant, Child and Adolescent Division, Office of Maternal, Child and Family Health, Bureau for Public Health, Department of Health and Human Resources.

The Project's vision statement is to promote optimal physical, emotional, cognitive, social, and spiritual well-being for children and youth throughout West Virginia.

The Project's mission statement is to support a collaborative partnership designed to foster and encourage youth to consider the health benefits of choosing abstinence.

The formal work of the West Virginia Abstinence Education Project (AEP) began in 1999 with the original HRSA Grant. Six local abstinence programs are funded in the State of West Virginia. The Project is designed as one facet of a *three pronged approach*, developed to address unintended teen pregnancy within a continuum of care as a primary prevention initiative. The Adolescent Health Initiative, the third prong to the approach is discussed in the following section.

**The Office of Maternal, Child and Family Health Offers Three Primary Prevention Approaches Within a Continuum of Care When Addressing Adolescent Health**



### *Capacity to Address Needs:*

The Project complies with the federal definition of abstinence education Section 510 of Title V of the Social Security Act. AEP also embraces The *Conceptual Framework for Adolescent Health* (developed in partnership by the Association of Maternal Child Health Programs and the State Adolescent Health Coordinators Network

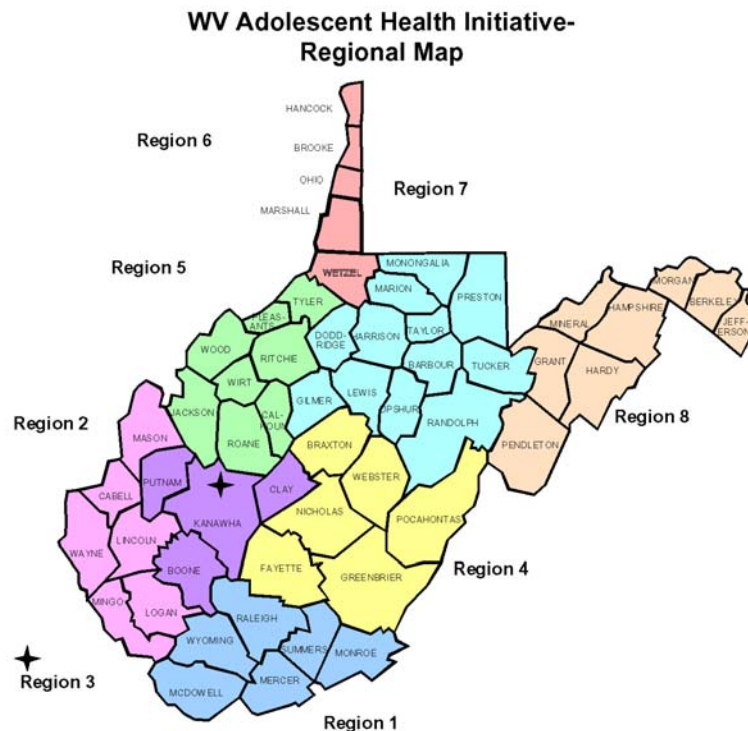


with funding from the Anne E. Casey Foundation) which provides a foundation for addressing adolescent health issues utilizing a youth development approach. *Healthy People 2010-Understanding and Improving Health-Critical Objectives for Adolescents and Young Adults* targets specific youth health outcomes to be addressed across programs providing a primary health prevention focus and a foundation for the regional networks throughout the state.

Local programs provide educational sessions and activities designed to address sexual health with focused attention on drug and alcohol use, a known factor in the early onset of sexual activity. Local Abstinence Educators work with schools to introduce these concepts to youth, parents, teachers, health care professionals, other regional networks, and civic groups. This multi-faceted approach strives to improve adolescent health. Scientific evidence based sources such as the Centers for Disease Control are required by all Section 510 local programs.

### **Adolescent Health Initiative**

The formal work of the Adolescent Health Initiative (AHI) began in 1988. Introduction of the developmental asset principles of Search Institute brought about a change in AHI's mission in 1993. The Office of Maternal, Child and Family Health funds a dedicated network of eight regional Adolescent Health Coordinators across the State of West Virginia.



The Initiative is designed to introduce, develop, train, and provide needed technical assistance to adults and youth with focused attention on improving adolescent health indicators while building asset-rich communities. The vision promotes optimal physical, emotional, cognitive, social, and spiritual well-being for children and youth throughout West Virginia. The mission supports community collaborative efforts designed to develop assets youth need to thrive and become successful across the State of West Virginia.

The key elements which form the foundation and framework of the AHI Strategic Plan include:

- ✚ A Conceptual Framework for Adolescent Health;
- ✚ Healthy People 2010-Understanding and Improving Health-Critical Objectives for Adolescents and Young Adults;
- ✚ Improving the Odds: The Untapped Power of Schools to Improve the Health of Teens, and;
- ✚ An Asset Approach to Positive Community Change-Search Institute.

#### **Regional Support Networks Designed to Promote Adolescent Health in WV**



WVDHHR/BPH/OMCFH/ICAH/Adolescent Health Initiative 2005

Further national attention came about with the development of a companion document entitled Improving the Health of Adolescents and Young Adults: A Guide for States and Communities through a partnership by the U.S. Department of Health and Human Services, the Centers for Disease Control, and the National Adolescent Health Information Center. This document is designed as a companion to *Healthy People 2010*. This framework assists communities in the establishment of priorities and action plans with outcome measures, which foster positive youth development.

A new instrument, entitled the System Capacity Tool, was pilot tested in three states during Fiscal Year 2004. This tool identifies six areas of capacity that must be in place in public health agencies, specifically maternal and child health programs, to provide the 10 essential public health services to support effective state adolescent health programs.

The intended outcome of this tool is an assessment of a program's existing capacity and the organizational and environmental supports needed to improve that capacity around adolescent health.

#### *Capacity to Address Needs:*

From a public health perspective, assessment leads to action and action leads to quality improvement. Documenting capacity allows for a chronicle or historical record of where a program started and provides consistency for staff and partners as well as the establishment of a baseline for measuring system improvement over time. Finally, program capacity in the context of other state level adolescent health regional networks builds capacity designed to promote partnering and needed collaborative efforts to improve adolescent health without duplication of effort.

The Office of Maternal, Child, and Family Health will be hosting a national facilitator, Ms. Kristin Teipel, from Konopka Institute on July 12, 2005 to begin completion of the Capacity Assessment Tool.

West Virginia is unique in the design structure utilized to address community needs. The state accomplishes program goals, objectives, and activities utilizing a regional network approach. Fourteen regional networks will be partnering and working in collaboration to address three of the six capacity building areas to include commitment to adolescent health, partnerships, and technical assistance. Each area is designed to address a set of discussion questions, complete a Strength, Weakness/Needs, Opportunities and Threat/Barriers (SWOT) analysis, and an element rating.

Facilitated regional network meetings will then be implemented to introduce the Capacity Assessment Tool, SWOT Analysis, and key elements across all networks throughout the state.

West Virginia will be the fifth state in the nation to complete the Capacity Assessment Tool, and the only state in the nation utilizing a regional network approach.

## **SEXUALLY TRANSMITTED DISEASES**

In CY2004, the Family Planning Program provided STD screening for 36,634 individuals:

- The incidence of GC in FP Program clients decreased (7.2/100,000 to 6.4/100,000) although positivity increased .02% from 2003-2004. In CY2003, the FP Program documented 115 positive GC results from 31,884 tests completed (0.36% or 6.4/100,000 population). These changes are likely due to focusing screening activities on a younger age, higher risk population.
- Chlamydia screening yielded similar results. In CY2004, 932 positives were documented in 31,884 tests (2.9% positivity). This rate was an increase of 0.7% from CY2003, again most likely due to intensified screening of younger, higher risk clients.
- The prevalence of syphilis declined among FP Program clients. In CY 2003, no positive cases of syphilis were documented in 4,808 tests.

### *Capacity to Address Needs:*

Routine testing and screening for STDs is stretching the FP Program budget because the costs of testing, the number of tests provided, and treatment has increased. A newer, single dose antibiotic is available for the treatment of chlamydia. This single dose leads to better compliance relative to the more traditional 14-pill regimen over seven days, but it is too expensive for the FP Program to provide.

The U.S. Preventive Health Services Task Force recommended in 2001 that all sexually active women aged 25 and under be screened routinely for chlamydia. Routine chlamydia/gonorrhea screening is offered in Family Planning Program clinics, in partnership with the WV Sexually Transmitted Disease Program and the Office of Laboratory Services. Screening and treatment of chlamydia is a public health priority, as noted by the continued federal funding of the national Infertility Prevention Project and state level screening programs. FP and STD Programs are facing new pressures to increase screening for chlamydia because of its increasing incidence, largely among young people, and the established link between chlamydia and infertility.

## **CERVICAL CANCER**

New and more accurate, but far more expensive, liquid-based Pap technology is fast becoming the standard of care in the United States but the Family Planning Program and most other government subsidized clinics cannot afford to offer it. The U.S. Food and Drug Administration approved liquid-based cytology (Thin Prep) for use in screening for HPV, chlamydia and gonorrhoea. Most privately insured women (75%) receive the liquid-based Thin Prep Pap test to screen for cervical cancer. However, Thin Prep is used in the public sector much less frequently than in the private sectors because of its cost relative to the conventional Pap test.

### ***Capacity to Address Needs:***

The FP Program currently provides over 41,000 conventional Pap smears per year for enrolled clients. Current funding levels do not permit the Family Planning Program to transition from conventional Pap smears to liquid-based Pap testing. A cost analysis comparing conventional Pap smears to liquid-based Pap smears will be completed. The analysis will replicate cost study models successfully used by the Virginia Department of Health in 2004.

## **FUNDING FOR FAMILY PLANNING SERVICES**

For more than three decades, the Family Planning Program has been an integral component of the public health care system, providing high-quality reproductive health services and other preventive health care to low-income or uninsured individuals who may otherwise lack access to health care. Subsidized preventive and reproductive medical care provided by Family Planning Program clinics prevents unintended pregnancies, reduces the need for abortion, lowers rates of sexually transmitted diseases (STDs), including HIV, detects breast and cervical cancer at its earliest stages, and improves the health of women, children and families.

Family planning has been a public health success story, across the nation as well as in West Virginia. Family Planning Program clinics not only provide quality health care services, but also save the government money. Investments in discretionary programs often lead to savings in mandatory spending. For every dollar spent on publicly funded family planning, \$3 is saved in pregnancy-related and newborn care costs to Medicaid.

However, the systematic under-funding of the federal Title X program now poses significant challenges to the survival of the WV Family Planning Program. Health care inflation has far outstripped funding for clinical services, which are further strapped as a result of new and expensive contraceptive technologies, improved and expensive screening and treatment for STDs and the expense of training/retaining qualified health care personnel in an era of nursing shortages. State fiscal crises continue to squeeze the Medicaid Program and the number of uninsured West Virginians continues to rise, adding to struggles to address the growing demand for subsidized family planning

services without corresponding increases in federal or State funding. WV Family Planning Program clinics are serving increasing numbers of patients without commensurate increases in funding – a situation that will only worsen as potential State funding curtailments of public health programs including Medicaid, possibly increase the number of individuals needing publicly funded health care services.

WV Family Planning Program clinics primarily serve low-income and uninsured women who do not qualify for Medicaid but earn too little to afford private health insurance. Eighty-seven percent (87%) of Family Planning Program clients have incomes below the federal poverty level and receive service at no cost and thirteen percent (13%) of clients have incomes below 250% of the federal poverty level and receive services at discounted rates.

Due to an expansion of Medicaid Managed Care in West Virginia, the Family Planning Program documented a significant reduction in the number of Medicaid claims billed through the program provider network, resulting in reduced revenue from the Medicaid Program. Providers now direct bill the Medicaid Managed Care Organizations, and write prescriptions for contraceptive supplies for Medicaid enrollees. While patients covered by Medicaid Managed Care may have adequate access to clinical family planning services, minor clients seeking reproductive health care can only be assured of confidential services in a Title X-funded Family Planning Program clinic.

The cost of contraceptives has skyrocketed. A recent survey by the Alan Guttmacher Institute found that the per client cost of purchasing contraceptive supplies rose 58% over the past six years, a calculation that was done prior to the availability of the newest contraceptive methods. The problem is two-fold:

- Long-lasting, effective, but expensive contraceptives that could lower the rate of unintended pregnancy are now available in the U.S. market, but the WV Family Planning Program cannot afford to offer all new methods. The Family Planning Program currently offers an injectable (Depo Provera) and a patch (Ortho Evra), but is not able to offer the vaginal ring (NuvaRing) due to the high cost of the product.
- The cost of oral contraceptives is likely to increase as well. Many patents are set to expire on popular oral contraceptives and manufacturers are poised to discontinue offering clinics the discounted products. Oral contraceptives are by far the most popular method used in Family Planning Program clinics.

### *Capacity to Address Needs*

Greater financial commitment (a minimum of \$8.3 million/year) for the WV Family Planning Program is needed to maintain the high quality preventive health care services provided to low-income women and men. No additional federal resources are available for this program. Especially in this time of tight State and federal budgets, investments made to strengthen the Family Planning Program will pay hefty dividends. For every

dollar spent on publicly funded family planning, \$3 is saved in pregnancy-related and newborn care costs to Medicaid. Increased financial commitment is needed to maintain these essential preventive health services.

**Public Expenditures for Contraceptive Services  
(The Guttmacher Report on Public Policy) (February 2005)**

State	FY 2001 Total (in 000s of Dollars)	% Change in Constant Dollars		FY 2001 Total Per Woman in Need
		Since FY 1994	Since FY 1980	
U.S. Total	\$1,261,351	36.5	-1.0	\$74.98
Alabama	26,597	38.0	37.1	96.73
Alaska	4,228	384.5	263.9	139.08
Arizona	16,697	239.1	30.3	49.54
Arkansas	16,321	168.7	29.3	97.93
California	322,367	184.8	40.6	146.11
Colorado	8,771	42.3	-29.5	37.05
Connecticut	16,967	40.7	21.1	102.24
Delaware	4,119	44.9	5.4	99.73
District of Columbia	1,279	-33.4	-75.8	35.69
Florida	46,113	-19.8	-10.8	52.03
Georgia	41,533	92.8	-16.8	84.61
Hawaii	1,339	-53.2	-87.5	21.59
Idaho	3,102	59.4	-7.6	37.32
Illinois	26,544	6.9	-38.5	37.65
Indiana	23,735	190.2	-11.9	65.81
Iowa	6,934	0.8	-39.8	40.77
Kansas	3,123	-32.4	-59.3	19.49
Kentucky	13,030	-17.5	-33.2	54.00
Louisiana	20,689	395.6	-20.6	68.00
Maine	6,971	-6.5	-8.9	87.95
Maryland	21,082	5.1	18.4	85.85
Massachusetts	29,579	58.6	20.5	89.06
Michigan	27,692	-8.4	-31.6	47.57
Minnesota	11,429	-21.6	-35.4	43.64
Mississippi	10,375	-14.0	-48.1	53.50
Missouri	30,876	37.8	45.1	88.46
Montana	2,829	-7.6	-50.7	51.19
Nebraska	3,073	3.5	-36.8	29.24
Nevada	4,818	-18.1	50.5	39.43
New Hampshire	2,826	-50.6	-25.6	43.23
New Jersey	26,726	42.5	-39.9	67.74
New Mexico	6,670	-2.0	-26.4	53.03
New York	96,072	-25.8	-11.2	78.88
North Carolina	27,234	0.0	11.4	58.24
North Dakota	1,580	-19.0	-41.4	38.58
Ohio	23,062	-19.3	-48.8	34.59
Oklahoma	24,083	142.8	58.8	111.69
Oregon	22,985	117.2	194.3	112.22
Pennsylvania	50,734	57.5	-10.8	70.74
Puerto Rico	3,398	-32.1	U	U
Rhode Island	2,676	180.8	20.8	39.41
South Carolina	43,717	134.3	88.9	175.32
South Dakota	1,724	70.7	-8.4	35.89
Tennessee	31,767	156.2	-4.6	95.34
Texas	65,656	-20.8	-29.1	48.73
Utah	3,923	-5.6	36.5	25.50
Vermont	4,093	2.3	6.7	109.29
Virginia	30,474	-9.1	9.4	82.00
Washington	17,229	16.8	6.8	52.20
West Virginia	6,611	-4.0	12.7	62.23
Wisconsin	14,518	3.0	-27.1	48.31
Wyoming	1,380	-28.5	-31.9	47.98

**Note:** U – unavailable. Women in need refers to women in need of publicly supported family planning services in 2002. This is defined as women who are aged 13-44, sexually active, fecund and neither intentionally pregnant nor trying to become pregnant; and are either younger than 20 or have a family income under 250% of the federal poverty level. Constant-dollar data is adjusted for inflation, using the Medical Care Price Index with \$1.00 in 2001 equal to \$1.29 in 1994 and \$3.64 in 1980. *Source: Public Funding for Contraceptive, Sterilization and Abortion Services, FY 1980-2001.*



## **BREAST AND CERVICAL CANCER SCREENING**

The West Virginia Breast and Cervical Cancer Screening Program (WVBCCSP) recently finished a qualitative study that assessed breast and cervical cancer screening barriers among women living in West Virginia. In order to qualitatively assess the barriers that women in West Virginia confront when trying to get screened for breast and cervical cancer, the WVBCCSP chose to convene focus groups. Focus groups were conducted in three different geographical locations around the state, including Beckley (representing the southern portion of the state), Charleston (central portion), and Morgantown (northern portion). By conducting the focus groups in various regions throughout the state, the Program was striving to capture a representative snapshot of West Virginia women. Additionally, in each region, two focus groups were held (for a total of 6). These groups were differentiated by age. One group consisted of women between the ages of 25 and 49 and the other group was comprised of women ages 50-64. These age categories were selected based on the age eligibility requirement for the WVBCCSP and selected levels of screening which are conducted at different age intervals (e.g. women under the age of 50 do not receive screening mammograms). Women who participated in the focus groups were also selected based on other WVBCCSP eligibility guidelines such as age, income, and insurance status.

While the following data are partial and preliminary, there were several emergent themes/barriers with regards to breast and cervical cancer screening. The following outlines these themes/barriers:

### **Barriers to Breast Cancer Screening (mammogram):**

- Cost/No Insurance
- Fear
- Pain
- Lack of Education

### **Barriers to Cervical Cancer Screening (Pap test):**

- Pain
- Cost/No Insurance
- Fear
- Embarrassment
- Male Doctors

Furthermore, most women did not know the risk factors for these diseases. If a correct risk factor was mentioned, they could not state why it was considered a risk factor. The human papillomavirus (HPV) – the main factor for cervical cancer was only mentioned by one person during the Morgantown focus group of 25-49 year olds. Other

groups talked about a “virus” or “herpes”, but not HPV specifically. A general lack of education on breast and cervical cancer appeared to be a major issue with the Beckley groups.

The focus groups also looked at ways to spread the message about the Program and about breast and cervical cancer screening in general. There were several questions which focused on designing brochures, distributing information, writing slogans, etc.

Each group of women stated that it was extremely important to receive a mammogram and Pap test and that these screening tools could save your life. Interestingly, not all women took their own advice and were screened routinely (see above barriers for reasoning).

Following is a discussion of three areas of importance with the Breast and Cervical Cancer Screening Program.

**1) Increase the Number of Mammograms Performed on Women Ages 50-64**

In 2005, the American Cancer Society estimates that 211,240 women will be diagnosed with invasive breast cancer and 40,410 women will die from the disease. Breast cancer is the second leading cause of cancer related deaths among women. Currently, there are over two million women living in the United States who have been treated for breast cancer. According to the West Virginia Cancer Registry, in 2001 just over 1,300 West Virginia women were diagnosed with invasive breast cancer and 306 women died from the disease. West Virginia ranks 19<sup>th</sup> in the nation in breast cancer mortality. The chance of a woman being diagnosed with breast cancer increases with age. According to the American Cancer Society, a woman has a 1:7 lifetime risk of developing the disease.

While there is no cure for breast cancer, experts agree that early detection is the best method of prevention. Screening mammograms, which are x-rays of the breast, are the most widely accepted early detection device in the fight against breast cancer. By having routine screening mammograms in accordance with accepted standards and based on recommendations of a physician, breast cancer can be detected early, even when a lump is too small to be detected by a woman or her physician. The five-year survival rate of a woman whose mammogram has detected a localized stage breast cancer is 98%. Early detection not only improves chances of survival, but it also increases treatment options.

***Capacity to Address Needs***

The Centers for Disease Control and Prevention (CDC) mandates that all National Breast and Cervical Cancer Screening Programs (NBCCEDP) must provide a

minimum of 75% of all screening mammograms paid for through federal funds to women ages 50-64. The West Virginia Breast and Cervical Cancer Screening Program is currently falling short of this goal. Recent Program data indicates that only 62.7% of the women receiving a Program paid screening mammogram are between the ages of 50 and 64.

As part of the Division of Perinatal and Women's Health, the WVBCSP offers services to uninsured and underinsured women who meet federal income guidelines. Women may be referred for diagnostic and/or screening mammograms from the Right From the Start Program or Family Planning Program. The goal of the Division is to offer comprehensive care to women using family planning services, breast and cervical cancer screening, and prenatal care, as a conduit.

During the spring and summer of 2005, the WVBCSP will begin planning activities to include: establishing a steering committee of interested partners, conducting focus groups to address barriers, develop potential intervention(s), and pilot test intervention(s) to determine efficacy. Focus groups will be funded from 2002-2003 unobligated funds and project implementation will be supported from the WVBCSP grant.

**2) Decrease the Percentage of Women Who Refuse Further Work-Up for Abnormal Screening Results and/or Treatment for a Diagnosis of Breast or Cervical Cancer**

In an effort to increase the number of positive outcomes, the WVBCSP closely monitors all women to ensure that they receive the necessary follow-up for abnormal screening results or necessary treatment for a diagnosis of cancer. Reasons for refusing follow-up for abnormal results and cancer treatment vary from person to person, but common factors involve denial and fear. A recent study on personal values and cancer treatment refusal also noted that all of the patients that participated in the pilot study cited that the advantages of treatment did not outweigh the disadvantages. Appalachian culture and health perspective may also play an important part in a patient's decision to refuse follow-up or treatment. In West Virginia, a state steeped in Appalachian culture, fatalism, medical mistrust, and poverty can be attributed to the refusal. It is important to keep in mind that a woman's chance of survival is greatly increased when disease is detected early also allowing for increased treatment options. Therefore, it is a priority of the WVBCSP to further reduce the number of women who refuse treatment and improve the health of West Virginia women.

The WVBCSP closely monitors women diagnosed with breast and/or cervical cancer and women who receive abnormal screening results. The goal of the WVBCSP is to reduce the number of women who refuse cancer treatment or follow-up of an abnormal screening result. At the time of this assessment 3.4% (CDC mandate is #3%) of WVBCSP enrolled women diagnosed with invasive cervical cancer, CIN II,

CIN III/CIS refused treatment and 1.1% refused additional diagnostic work-up following an abnormal Pap test screening result (CDC mandate is #2%). Data indicates that 0.0% of WVBCCSP enrolled women diagnosed with breast cancer refused treatment (CDC mandate is #3%) and 2.5% refused additional diagnostic work-up following an abnormal breast screening result (CDC mandate is #2%).

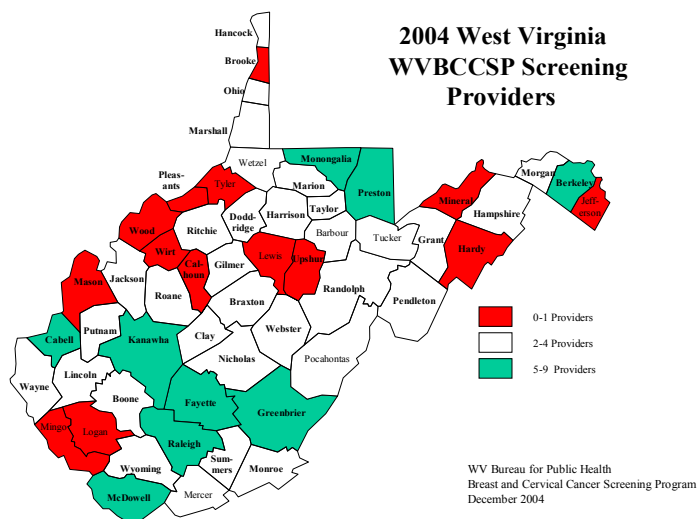
*Capacity to Address Needs:*

As part of the Division of Perinatal and Women's Health, the WVBCCSP offers services to uninsured and underinsured women who meet federal income guidelines. All programs within the Office of Maternal, Child and Family Health seek positive outcomes for their clients. There is a wider variety of treatment options and a greater chance of survival when women are diagnosed early and seek timely treatment. This benefits the health of mothers, children and families throughout the state.

The WVBCCSP will continue to prioritize the case management of women identified by the Program Pending Report. These women will be contacted by phone and/or letter to lessen fear and explain the importance of obtaining treatment for their abnormal test results. This activity will be funded by the WVBCCSP grant.

**3) Sufficient Availability of Specialty Providers**

West Virginia is experiencing a shortage of physicians and health care providers (see maps pages 6, 7). As a result, the WVBCCSP has encountered problems with sustaining an appropriate number of physicians to provide breast and cervical cancer services for the Program eligible population. The Office of Women's Health indicates that there are only 190 OB/GYNs (National Women's Health Indicator's Database, 2000) in West Virginia. This means that there is approximately one OB/GYN to every 5,000 women. The Program has experienced significant problems in recruiting screening providers in the Mid Ohio Valley of West Virginia (Pleasants, Wood, Wirt, Ritchie, Roane, and Calhoun Counties). In total, there are only eight screening providers serving these six counties. Pleasants County does not have a screening provider within its borders.



One of the biggest impacts the physician shortage has had on West Virginia's women is that in some areas of the state, women must travel significant distances in order to receive both screening and referral services. Women who have no form of transportation experience an even greater burden because outside the urbanized areas of West Virginia, public transportation systems are nearly non-existent. Geography also poses a problem. West Virginia's mountainous terrain makes travel difficult from rural areas to the more urbanized parts of the state. Travel on non-interstate roads during winter months is difficult and sometimes treacherous. The state's geography also makes traveling from the northern-most aspect of the state to the southern-most aspect a 7½ hour drive.

#### *Capacity to Address Needs:*

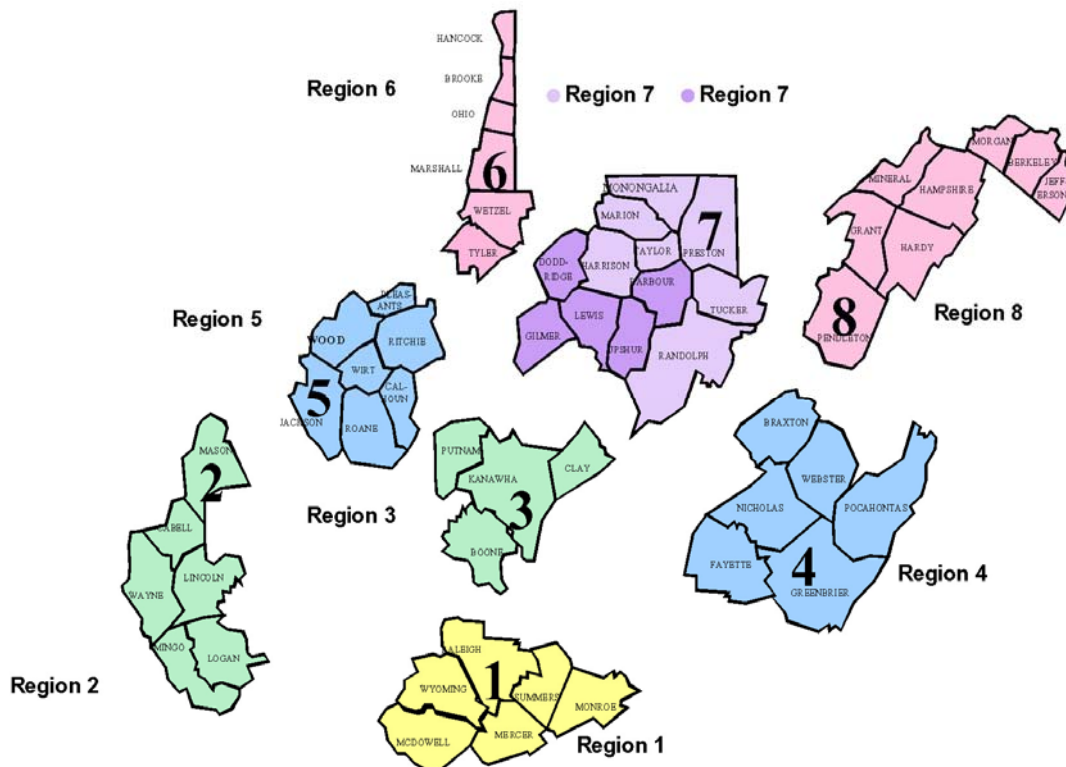
At the time of this assessment WVBCCSP has identified only 47 breast surgeons to provide services for its women. Many of these surgeons are clustered in areas with higher populations, leaving many women significant distances to travel for services. In addition, twelve of the fifty-five counties have only one screening provider site within its county borders. Ideally, no woman would have to travel more than thirty minutes from her home in order to receive services.

As the Office of Maternal, Child and Family Health, all programs strive to provide high quality, accessible care to its clients. Health professional shortages impact all programs. By increasing the availability of providers in the Mid Ohio Valley, OMC FH programs will be more readily accessible to West Virginia residents.

During the 2005-2006 fiscal year, WVBCCSP will work to increase the number of available breast surgeons by at least 10% and increase the number of screening providers in the Mid-Ohio Valley by five provider sites. According to data from the US

Department of Health and Human Services, Bureau of Health Professions (see attached map), all but one county in this region is designated as a Health Professional Shortage Area. Providers will be recruited through Cancer Information Specialist referrals and active recruitment by the Program Director. These activities will be funded through the WVBCCSP grant.

The WVBCCSP contracts with WVU or health care agencies to provide nine (9) Cancer Information Specialists (CIS) to cover 8 regions who are strategically located throughout WV (see following map). The CIS is responsible for community education/awareness and outreach in order to increase enrollment in the WVBCCSP and decrease the burden of breast and cervical cancer in their regions by promoting early screening and detection with a special emphasis on never or rarely screened women. The CIS develops and implements community education and awareness activities with assistance from a wide range of community partnerships and volunteer support. This position also acts as a volunteer coordinator by recruiting, training, and retaining volunteers in their assigned region. WVBCCSP providers are given assistance by the CIS staff, ranging from annual site visits to policy and procedure updates and clinical outreach. The CIS also acts as a communications agent by arranging and promoting public service announcements, making public appearances/speeches, and providing radio and television interviews.



**B. STATE MCH POPULATION GROUP:  
CHILDREN AND ADOLESCENTS**

## **B. STATE MCH POPULATION GROUP: CHILDREN AND ADOLESCENTS**

Following is a broad assessment of children's issues in West Virginia in the following areas:

- **SCHOOL READINESS**
- **HEALTH CARE COVERAGE**
- **HEALTH HOME**
- **ASSURING ACCESS TO HEALTH CARE**
  - School Based Health Care
- **CHILDHOOD LEAD POISONING**
- **ORAL HEALTH**
- **MENTAL HEALTH**
- **OBESITY**
- **ASTHMA**
- **INJURIES**

### **SCHOOL READINESS**

The first five years of life are critical to a child's lifelong development. Young children's earliest experiences and environments set the stage for future development and success in school and life. Early experiences actually influence brain development, establishing the neural connections that provide the foundation for language, reasoning, problem-solving, social skills, behavior and emotional health.

Families and communities play critical roles in helping children get ready for school. Children from families that are economically secure and have healthy relationships are more likely to succeed in school. Schools can improve the readiness of young children by making connections with local childcare providers and preschools and by creating policies that ensure smooth transition to kindergarten.

Former Governor Wise, in 2001, charged the Governor's Cabinet on Children and Families with improving child and family services, promoting collaboration among state agencies, and maximizing resources to support families and nurture children. As a consequence, a committee was formed to assure children have access to quality early care and educational programs to ensure their readiness for school and lifelong learning. The West Virginia Department of Education and the West Virginia Department of Health and Human Resources were jointly made responsible for implementation and oversight of a pre-kindergarten system (WV Code § 18-5-44). Together the two agencies developed an Early Learning Standards Framework (ELSF) for preschool children designed to guide caregivers and teachers in planning quality learning opportunities. The plans developed in West Virginia largely mimic the National School



Readiness Indicators Initiative, sponsored by the David and Lucile Packard Foundation, the Kauffman Foundation and the Ford Foundation.

The National Plan being followed by WV includes tracking and measuring five indicators of school readiness:

- Physical well-being
- Language development
- Cognition and general knowledge
- Social and emotional development
- Approaches to learning (creativity, cooperativeness, curiosity).

Readiness Services – Health, which is the assignment of the Office of Maternal, Child and Family Health to spearhead, have indicators listed below:

- 3% of children under age 6 are without health insurance. As of 2004, only 4.5% of West Virginians between ages 1 to 18 are without insurance, and 1% are under age 6.
- 8.5% of infants born weigh less than 2500 grams.
- 13% of births are to women who receive late or no prenatal care.
- 79% of children 19-35 months have been fully immunized (Kids Count 2004/Casey Foundation).
- 98% of newborns are screened annually for risk of post-neonatal mortality and developmental delay. Source: Birth Score Annual Reporting – WVU School of Medicine, Department of Pediatrics. Of those at risk of developmental delay, 25% were provided intervention including home visitations or Early Intervention referrals (Part C) due to risk identification.

### *Capacity to Address Needs*

West Virginia is fortunate to have many components of a comprehensive system for young children already in place and has been effective in improving the lives of its children. The infant mortality rate has continued to decline from 31.4% in 1950, to 11.8% in 1980 to 7.3% in 2003. Over 93% of West Virginia's children and adolescents were insured at some point during the year.

There are 39,000 infants and toddlers, 0 to 3, who have Medicaid coverage within West Virginia and of those, 73%, received an EPSDT screen. In WV, an EPSDT/HealthCheck examination includes developmental screening.

According to CHIP/Medicaid data there were 35,320 children ages 0-18 enrolled during 2003 and 205,331 children ages 0-18 enrolled in Medicaid for the same time period. In FY 2003, WVCHIP made special outreach efforts in the counties with a

higher proportion of uninsured children. Fifteen (15) of WV's 55 counties accounted for 13,612 (or 63%) of the 21,623 estimated uninsured children eligible for CHIP or Medicaid in 2002.

WVCHIP has compared annual enrollment changes in the 15 targeted counties for this period and found that 10 of these 15 were above the median growth for all 55 counties and 7 of 15 showed increases above the median in number of children never before enrolled in CHIP/Medicaid. (WV CHIP Annual Report 2003).

- 75% of the infants and toddlers under 3 years of age (0 to 3) served by Part C-Early Intervention/Birth to Three are Medicaid beneficiaries. Source: BTT Enrollment Data, OMCFH.

#### Readiness Service: Language Development

Because we are all concerned about the educational success of West Virginia's children, and reading, writing and talking skills are keys to success in school and in life, West Virginia engaged in an initiative to: (1) study how young children learn language and literacy skills and why it is important; (2) identify promising literacy programs in the nation; (3) identify what is going on in West Virginia; and then (4) determine what we can do to improve the language and literacy skills of our youngest children. This study was conceived and is funded by the Claude Worthington Benedum Foundation.

We used to believe that children learned to read and write after they entered elementary school and received specific instruction. Language skills were believed to develop first, followed by reading and then writing. But we know differently now. Children gain significant knowledge of language, reading and writing in the first three years of life.

Reading and writing development is closely linked to a child's earliest experiences with books, stories and spoken language. Young children rely on the adults around them to provide them with caring, nurturing and enriching environments in which to explore and learn. The building blocks for language, reading and writing development are the interactions that young children have with the adults in their lives and with books, paper and crayons.

Early literacy does not mean early reading. Our current understanding of early language and literacy development has provided new ways of helping children learn to talk, read and write. But it does not advocate "the teaching of reading" to younger and younger children.

If children do not learn the foundation skills needed for reading and writing in the first three years of life, they are more likely to have reading difficulties in school. More than one in three children has significant difficulties learning to read and have difficulties

“catching up” with peers if these problems are experienced early in childhood. Thirty-eight percent of West Virginia’s fourth graders scored at a basic reading level. The basic level means partial mastery of knowledge and skills that are fundamental for proficient work at each grade. Thirty-five percent of fourth graders scored below the basic level. Only twenty-eight percent of West Virginia’s fourth graders scored as proficient or advanced in their reading performance.

Children at greatest risk for reading difficulties are those from low-income families and minority families, those who have families with limited English proficiency, those with hearing and other language impairments, and those whose families have difficulty reading.

Being a good reader in the early grades is one of the strongest predictors of later success in school. If you are a poor reader by the end of first grade, you are highly likely to remain a poor reader. Studies indicate that children who are poor readers are more likely to drop out of school.

This West Virginia research provides compelling evidence that the vast majority of reading problems faced by youth and adults could be avoided if all young children had access to a wide variety of enriching experiences with spoken and printed language and relationships with caring and responsive adults.

*Capacity to Address Need:*

Many individuals and groups in West Virginia are working to improve the literacy and language development skills of our youngest children. Some of these efforts include:

- West Virginia Public Broadcasting offers many programs, including Sesame Street, Barney and Friends, Teletubbies and Reading Rainbow.
- Several health care centers use the national Reach Out and Read Program.
- Head Start, Starting Points Centers and various home-based parenting education programs, like Parents As Teachers, have a literacy component.
- Public libraries offer special reading programs for young children.
- West Virginia University Extension has a pilot literacy program called Family Storyteller.
- Read Aloud West Virginia is a broad-based, volunteer effort that seeks to motivate children to want to read. Its largest component, Readers in the Schools, involves trained volunteer readers who visit classrooms to share their love of reading with students.

The West Virginia Children's Coalition, comprised of child serving agencies, parents, and insurance, has recommended that the screening instrument used for EPSDT populations be adapted by all insurers for medical practitioner use, to assist in identifying children with needs. The use of a uniform screening tool would provide the following:

- Identify infants and children who may need social or developmental care across all payors.
- Differentiate between those with need of follow-up and those engaged in on-going services.
- Provide an efficient means of administering screening.
- Provide information that can lead to action across the total population.

### **HEALTH CARE COVERAGE**

According to 2000 Census data, there are 402,393 children under age 18 in WV. As of June 30, 2004, 215,058 children were eligible for Medicaid and EPSDT services. Of that number, 162,765 are enrolled in Managed Care Plans. West Virginia has a history of leadership in assuring health care access to children. Even before Title XXI, the federal legislation that expanded health insurance for children, West Virginia sponsored health services for low income, medically indigent children who were not eligible for Medicaid. This was made possible using Title V resources, state legislative appropriation, and the cooperative community spirit of the medical practitioners. In any given year, the Office of Maternal, Child and Family Health purchased medical visits for 60,000 children.

Although this government program, called Pediatric Health, had a limited benefit package, it served as a vehicle for routine primary pediatric care and to identify children with more complex medical conditions. In addition, the OMCFH established a partnership in 1997 with Blue Cross-Blue Shield to expand the number served, using the Caring for Kids fiscal resources.

The advent of CHIP created an alternate financing stream but also created new challenges. Eight (8) forums were held throughout the state to discuss program access. Parents and leadership from Family Resource Networks, Primary Care Association, local health departments, representatives from Maternal, Child and Family Health, etc. all gathered to discuss enrollment processes, identify barriers to enrollment, and to develop outreach strategies.

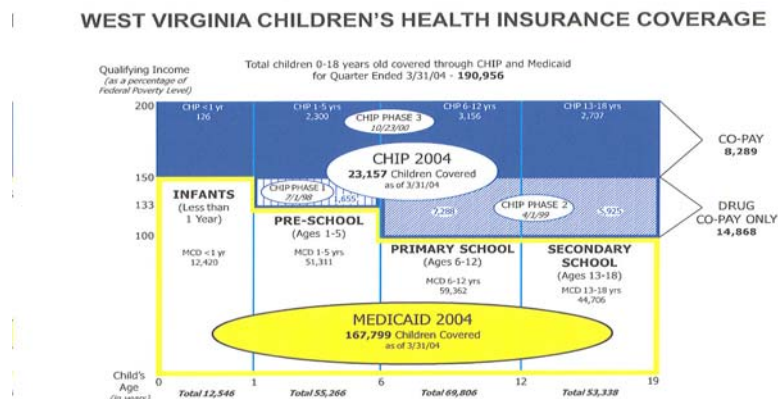
Several barriers to enrollment were identified, as shown in the next chart, however a notable enrollment practice was that an applicant would be evaluated first for Medicaid and then, if ineligible, evaluated for CHIP eligibility.

Barriers to Enrollment in Medicaid	
Barriers Related to Knowledge	Barriers Related to Program Perception
Thought Medicaid was for people on Welfare. Thought or was told family was over eligible income level. Did not know about Medicaid. Believed family was not eligible.	Don't need help from government programs. Someone in my family thought it would not be a good idea. Was on Medicaid before and was disenrolled.

Under the leadership of the WV Children's Coalition, several actions occurred:

1. Continuous coverage for a period of 1 year from point of eligibility.
2. A shortened application that was used to determine eligibility for Title XIX or Title XXI.
3. Physician practices distributed enrollment applications.
4. The MCFH Pediatric Program Specialists, who serve as liaisons with the medical community, distributed program brochures and applications and educated medical practitioners.
5. MCFH did mailings to 60,000 youngsters participating in the Title V Pediatric Health Services Program that included CHIP applications.
6. Schools were used as distribution sites.
7. Community-based workforce was hired to assist with public informing and applications.

As a result of this community effort, 93% of WV children have some type of health coverage. As of the end of March, 2004, 23,157 children were enrolled in CHIP. This represents 5.1% of the children's population in WV.



### *Capacity to Address Needs:*

While West Virginia has been extremely successful enrolling eligible children in the West Virginia Children's Health Insurance Program (WVCHIP) and Medicaid programs, there are still challenges facing medical care access for children in West Virginia. During the last six months of 2001, an estimated 13,733 children were unable to obtain medical care when they needed it. Because most of West Virginia's 55 counties are designated medically underserved meeting the needs of chronic or disabled population is impaired by the shortage of medical sub-specialty providers such as occupational therapists, physical therapists, and speech pathologists.

OMCFH, through its HealthCheck Program that houses the Pediatric Program Specialists, continues to outreach into the medical community educating practitioners on medical health financing programs that may be available for their patients. This includes referral to CSHCN clinics that are held throughout the state, which are staffed by medical specialists.

### **HEALTH HOME**

As described by the American Academy of Pediatrics (AAP), a medical home is not a building, house, or hospital, but rather an approach to providing comprehensive primary care. A medical home is defined as primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. In a medical home, a pediatric clinician works in partnership with the family/patient to assure that all of the medical and non-medical needs of the patient are met. Through this partnership, the pediatric clinician can help the family/patient access and coordinate specialty care, educational services, out-of-home care, family support, and other public and private community services that are important to the overall health of the child/youth and family.

Although WV's Medicaid population has a benefit plan equal to or better than most other coverage sources in the state, 47% do not participate in HealthCheck (EPSDT) well-child exams (CMS 416 for 2003). This is in spite of the presence of 455 medical providers, who offer HealthCheck services evenly distributed across the state.

Another indicator of the lack of health homes is the number of emergency room visits. The total number of emergency room (ER) visits in West Virginia was approximately 1,065,000 in the fiscal year of 2003 for a population of 1.8 million people. ER visits are graded on a scale of 1 through 7 which denotes severity of the injury or illness causing the visit, 7 being the most severe. Grades 1 through 3 represent conditions which may not have required intervention by a medical provider or for which the appropriate intervention would not be a visit to the ER. National statistics from the Centers for Disease Control (CDC) indicate that only 34% of ER visits are for "urgent" conditions.

The number of WV emergency room visits per 1,000 population increased from 555 in 1999 to 610 in 2002. To put this in context, the national rate in 1999 was 365 visits per 1,000 population; the national increase was much smaller, to 382 per 1,000 population. This has occurred in an environment of increasing Medicaid and CHIP enrollment, increasing insurance coverage, and a growing number of Medicaid-eligible children in managed care plans, all of whom are being encouraged to use primary preventive health care.

*Capacity to Address Needs:*

The OMCFH administers the WV HealthCheck Program under contract with the WV Bureau for Medical Services (Medicaid). HealthCheck has the following objectives:

- Creation and maintenance of protocols for well-child exams based on federal legislation, pertinent regulations and guidelines of the American Academy of Pediatrics;
- Recruitment of medical practitioners to provide well-child exams;
- Training of those practitioners and their staff on the HealthCheck protocols, technical assistance, and quality assurance activities;
- Outreach and informing of parents of Medicaid-eligible children on the benefits of preventive health care, and assistance to these families in accessing preventive well-child exams and referred services; and
- Record keeping and reporting to the WV Medicaid Program and creation of the annual report for the Centers for Medicare and Medicaid Services (CMS).

With the partnerships developed with Medicaid, the Public Employees Insurance Agency (PEIA), the Office of Health Promotion, etc., the Infant, Child and Adolescent Health (ICAH) Division will be positioned to encourage the Medical Home concept. Also, ICAH houses the Early Childhood Health Project (ECH). ECH is WV's HCCA/SECCS project. ECH works to improve the well-being of children 5 years of age and younger. ECH seeks to achieve this objective through collaboration with child serving agencies and a partnership between DHHR and the WV Department of Education. This collaboration, known as Partners Implementing an Early Care and Education System (PIECES), allows ECH to concentrate on health and safety issues and be involved in the efforts of WV's child care licensing and education programs without being duplicative.

Currently WV is transitioning its HCCA project into SECCS, per federal direction from MCHB. The final activity for the project will be training of child care providers on physical activity and nutrition, vision screening and oral health. Regarding the SECCS grant, WV is in a planning year during which we will be engaging our colleagues in PIECES and the health community in discussions on the activities which will be the most helpful to the overall effort. These discussions will be the basis for the implementation plan and application for funding.

## **ASSURING ACCESS TO HEALTH CARE**

### **School-based Health**

School-based health centers in West Virginia were first established in 1994 through a partnership of the West Virginia Bureau for Public Health and the Claude Worthington Benedum Foundation. During a three-year pilot phase, 14 programs were funded, along with research and technical assistance support through the Marshall University School of Medicine. In 2004, the number of school-based health centers expanded to serve 47 schools in 18 counties as a result of continued interest and support at the community, state and federal levels.

In order to bring partners interested in school-based health care together, the West Virginia School-Based Health Assembly was formed in 1995, and now serves as the lead membership organization and unified voice in the state for the advancement of school-based health care. As a founding member of the National Assembly on School-Based Health Care, West Virginia is a leader in this field.

School-based health centers are health clinics located in schools that provide both preventive and primary care to students to meet their health needs. West Virginia's school-based health centers:

- Support the school's education mission by ensuring that students' health care needs are met, and that barriers to learning are reduced;
- Link students to a medical provider and other community services by coordinating with other providers and organizations;
- Use a team approach to providing care through a variety of health professionals including school nurses and counselors;
- Follow a set of standards for care, including parental consent for enrollment and treatment; and
- Are sponsored by primary care centers and hospitals and receive funding from state, federal, private sources, in-kind donations, and patient revenue.

More than twenty percent of WV's public school children require regular and ongoing health services during the day. Due to their unique setting and proximity to children, school-based health centers address children's health needs by providing comprehensive primary care services. During 2003-2004, 37 school-based health centers served 47 schools in 18 counties.

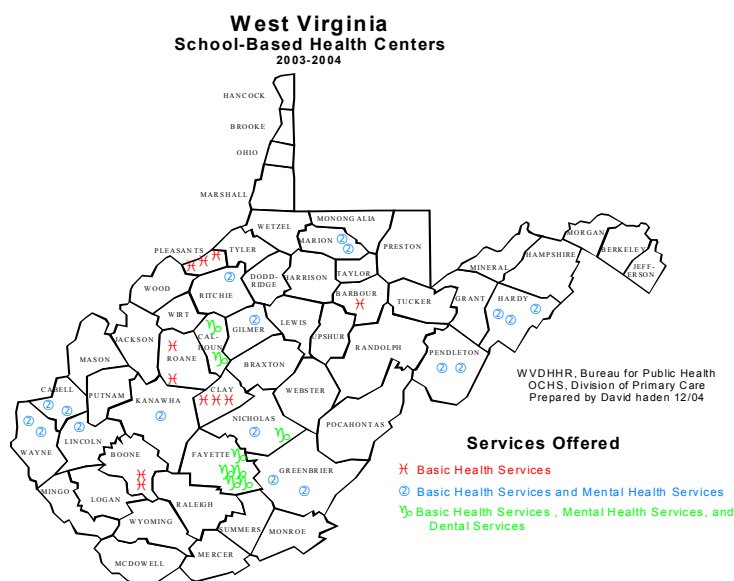
- During the 2003-2004 school year, there were 63,567 student visits to school-based health centers, as well as 4,000 visits from other school staff and family members.
- Seventy-five percent (75%) or 19,241 of students in schools with a school-based health center had parental consent to receive health services at the



centers. (Please note: contraceptive care is not offered through school-based health clinics).

- Sixty-four percent (64%) of enrolled students used their school-based health center on at least one occasion during the school year.
- WV's school-based health centers provided meaningful access to uninsured children (1,484), in addition to those children covered by Medicaid (4,493), WV CHIP (818) and private insurance (5,544).

West Virginia's school-based health centers help to screen and detect health problems early to prevent more expensive interventions in the future.



- Some 2,239 students received a comprehensive exam that met EPSDT guidelines and included a risk assessment to screen for behaviors that are responsible for most of the preventable health issues that occur during adolescence. An additional 1,863 students received a partial sports exam.
- A total of 2,095 immunizations were administered to students in schools with school-based health centers. An additional 663 immunizations were provided to school staff and area school students.

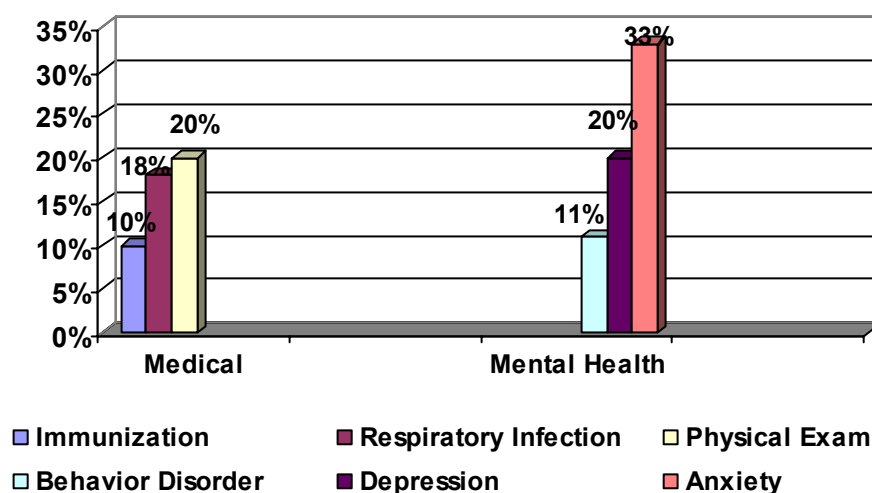
A variety of health promotion activities are offered through school-based health centers including tobacco use prevention, healthy lifestyles, and anti-bullying programs. Centers work to educate students on the self-management of chronic diseases, such as asthma and diabetes.

- Approximately 5,072 students using school-based health centers were assessed for their Body Mass Index (BMI). The results show that 41% were at-risk or were overweight. Health and wellness guidance was provided.
- During 2003-2004 school year 1,394 students received mental health counseling services with an average of 6.3 visits per user.

Experts agree that children's academic success is directly related to his or her health. In addition to keeping children healthy and in school, school-based health centers have demonstrated other positive impacts including:

- Decreased school absenteeism associated with chronic diseases and acute illnesses.
- Fewer emergency room visits by students needing primary care.
- Reduced parental time off from work associated with health care visits.

#### **Needs Most Commonly Addressed in WV SBHCs 2003-2004**

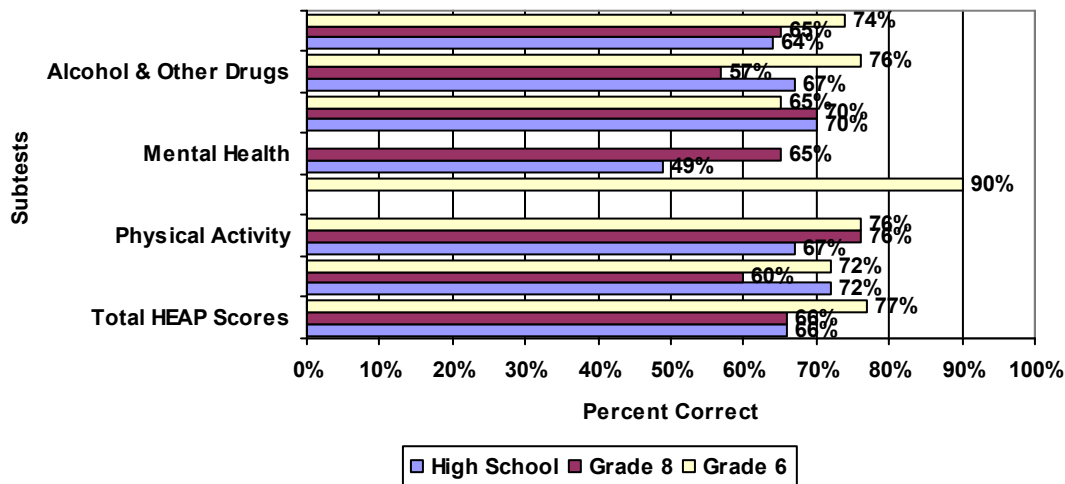


In the 2002-2003 school year, the West Virginia Department of Education's Office of Student Services and Health Promotion planned and implemented its first statewide assessment of health education. A team of health educators from across WV planned and implemented this assessment. Assessment items were taken from the State Collaborative on Assessment and Student Standards Health Education Assessment Project (SCASS-HEAP). Health education content areas and items were selected based on the extent to which they aligned with the WV Health Education Content Standards and Objectives (CSOs). All grades included items on the health education content areas of nutrition, physical activity, growth and development, alcohol and other

drugs and tobacco. Grades 6 included items on injury prevention and 8<sup>th</sup> grade and high school versions included questions on mental health. Seven additional items, taken from the beginning of the Youth Risk Behavior Survey, were also used. These items asked for information on students' age, sex, grade, race and height and weight.

A total of 51 counties and 242 schools were recruited to participate (county response rate =93%; school response rate =53%) and over 17,000 sixth, eighth and high school students completed the HEAP assessment in the spring of 2003. Mean scores and percent correct for an overall score and for each content area and question were calculated. The criterion of 80% correct was established as the standard to be achieved. Percents over 80 were labeled as “exceed the standard”; those in the 70’s were labeled as “almost met the standard”; and percents under 70% were labeled as “standard not met.”

**Statewide Grade Summary (Percent Correct)**



Mental Health questions **were not** given to sixth grade students.

Injury prevention questions **were not** given to eighth grade and high school students

An in-depth look at the questions across all content areas and grade levels, for which students failed to meet the standard, revealed deficiencies in the following areas:

- Identifying the short and long term consequences of tobacco and drugs;
- Identifying risks associated with sexual activity (8<sup>th</sup> grade);
- Analyzing the effectiveness of various birth control methods for both pregnancy prevention and protection against STDs (high school);
- Identifying accurate sources of health information;
- Understanding a food label;
- Linking a particular physical activity to a specific fitness outcome;
- Identifying recommended physical activity goals;

- Analyzing media/advertisements; and
- Identifying effective ways to deal with stress.

#### *Capacity to Address Needs:*

School-based service centers are an efficient and proven strategy for assuring a range of needed services are available to school age children. This includes health care, mental health services, dental care, and linkage to social services. The school-based services subcommittee of the Health Umbrella Group previously submitted a report in the spring of 2003 recommending action in this area. The Governors' Citizens Advisory Council (GCAC) independently identified the school-based services issue as the highest priority among issues considered for action at the Cabinet level. The Cabinet has established a cross-agency working group in this area on which OMCFH is represented. Achieving the recommended results will require changes at the state and community level and will also require a willingness among community-based agencies and providers to develop new, more collaborative ways of serving children and families. Financing policies for school-based centers must provide incentives for integrating services and emphasizing prevention.

#### **Recommended Strategies**

- Assure that all children receive comprehensive and periodic screening for health and development using the HealthCheck (EPSDT) protocols and forms;
- Provide appropriate mental health services through school based centers and the out stationing of mental health professionals in schools;
- Adopt standards and definitions that define different levels of school based health and wellness centers;
- Pilot a coordinated, countywide system of care to improve the health and wellness of children using school-based centers as service hubs;
- Develop one or more model financing plan that provide tools for school-based centers in accessing available funding streams;
- Provide incentives for local development of school based health centers:
  - (1) Establish a "base funding level" for state grants to school-based health centers freeing up funds for additional grants
  - (2) Appropriate additional state funds and free up federal funds for the development of school-based health centers
  - (3) Require local agencies and private providers to jointly develop a comprehensive plan for children's health and wellness that addresses the redeployment of staff and maximization of existing resources as a precondition of receiving state grant funds for any new school-based health centers
- Explore Medicaid waiver options for establishing capitated payment systems to support preventative school-based services; and

- Use available state data to provide evidence of effectiveness of school-based services.

## **CHILDHOOD LEAD POISONING**

Since 1995, West Virginia (WV) childhood lead screening and surveillance activities have been supported by a grant from the Centers for Disease Control and Prevention (CDC). While West Virginia's Childhood (childhood meaning up to 72 months of age) Lead Poisoning Prevention Project (CLPPP) is administered by the Children's Reportable Disease Program housed in the Office of Maternal, Child and Family Health, partnering occurs with multiple offices within the Bureau for Public Health and throughout the state.

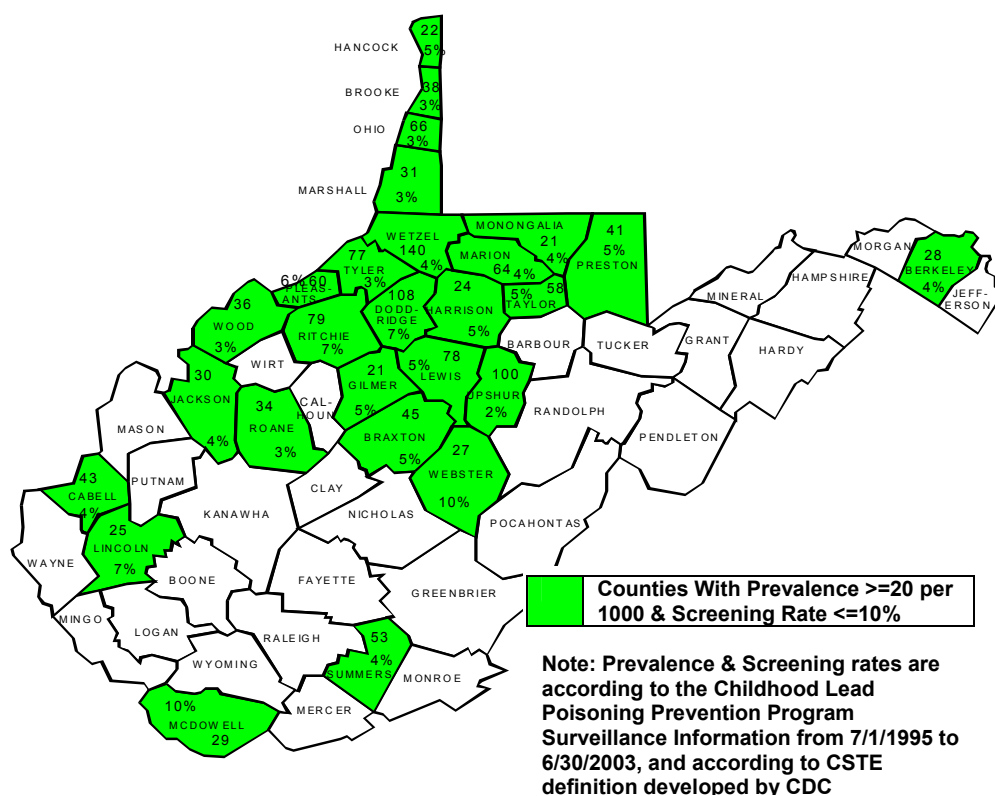
In West Virginia, childhood blood lead test results and information are reported to the State's Children's Reportable Disease Program. Currently, the Program focuses on the following objectives:

- To implement a statewide elimination plan to eradicate childhood lead poisoning in West Virginia by 2010;
- To decrease the number of new cases of lead poisoning (greater than or equal to ten (10) mcg/dl) to less than one percent of the tested population of children 0 to 6 years of age;
- To decrease less than three percent of children in targeted high risk population by the year 2010;
- To increase blood lead level (BLL) testing rates (currently BLL testing rates in children are low) and identify children 0 months to 6 years of age who are at high risk for lead poisoning;
- To geographically target program activities in identified high risk areas (increased screening rates are essential for targeted activities);
- To enhance primary prevention activities to focus on addressing lead hazard problems in old housing and primary prevention for childhood lead poisoning;
- To encourage local organizations to apply for HUD grants and address old housing issues in their communities;
- To assure that all childhood blood lead test results are reported following established protocols;
- To collect complete demographic data (including county of residence) for all children screened for blood lead levels;
- To continue epidemiological analysis of collected information in order to monitor outcomes of lead poisoning;
- To provide epidemiological interpretation of the results of analysis;
- To disseminate information and results of surveillance activities to interested parties,
- To evaluate existing program activities based on findings;

- To provide feedback to providers and the public about the burden of childhood lead poisoning in their own communities; and,
- To support Senate Bill 216 requiring a statewide screening plan to screen all children at risk of lead poisoning.

According to CLPPP surveillance outcome analysis data from 1 July 1995 to 30 June 2003, 27 of West Virginia's 55 counties have a prevalence of  $\geq 20$  per 1000, with screening rates of  $\leq 10$  percent in children 0 to 72 months of age.

### Counties With Prevalence $\geq 20$ per 1000 & Screening Rate $\leq 10\%$



### *Capacity to Address Needs:*

In January 2002, Senate Bill 216 mandated screening of all high risk children 0 to 6 years of age to identify lead poisoning. Reporting of all blood lead levels with complete demographic information (including county of residence) was included in the Rules.

Issues of low screening rates and the need for ongoing identification of children with elevated blood lead levels has been discussed with CLPPP partners and providers. Public and provider educational activities regarding childhood lead poisoning prevention continue. Physicians often refer children to off-site laboratories for collection of the specimen resulting in a lack of follow-through by the patient/family, which has been a factor contributing to low screening rates. Providers were asked to test children 6 years and under for initial blood lead levels using either venipuncture, fingerstick or the filter paper collection method. The confirmatory test is more reliable if done by venipuncture.

Planned efforts are underway to partner with local agencies and primary care facilities in high risk counties to screen young children for lead poisoning and to provide follow-up services for children who have positive results for lead poisoning.

The CLPPP has the capacity to match Medicaid-eligible data with the CLPPP database to identify and track outcomes in Medicaid-eligible children who are at high risk for lead poisoning. Low BLL testing (this testing needs to be with blood lead specimen and not with risk questionnaire) rates in Medicaid-eligible children has been identified as a serious problem. Providers have been requested to increase testing in children by obtaining a blood lead specimen.

In addition to blood lead level testing, surveillance in West Virginia also includes case management and environmental assessment. All children who are identified with elevated BLLs of greater than or equal to ten (10) mcg/dL are provided case management. Environmental assessments are conducted whenever a child's blood lead level is confirmed elevated at twenty (20) mcg/dL or when a child has two consecutive confirmed blood lead levels of fifteen (15) mcg/dL. Even though this is the protocol, depending on the presence of risk factors, the CLPPP also conducts case management services for children with BLLs between ten (10) and fifteen (15) mcg/dL.

Since environmental assessments, in part, investigate the genesis or cause of the blood lead poisoning, surveillance provides tracking of these identified sources. Lead paint is still the most common source of lead poisoning in children in West Virginia.

### **ORAL HEALTH**

The Office of Maternal, Child and Family Health (OMCFH)/Oral Health Program (OHP) is involved in many activities to improve West Virginia's oral health.

### The Children's Dentistry Project (CDP):

It has been stated many times that an ounce of prevention is worth a pound of cure, and that saying is true for oral health. Most of the power to prevent oral disease rests with the individual. Before people can adopt desirable health behaviors, they must have knowledge of those behaviors and the methods to implement them.

WVCHIP reports that during FY 2003-2004, 95% of enrollees have participated in obtaining dental services. Medicaid enrollees for FY 2002-2003 (newest data available) reports that 42% children between the ages of 3 and 20 have utilized a dental service.

#### *Capacity to Address Needs:*

CDP promotes public awareness to West Virginia youth through oral health education in schools and other venues, using teaching modules developed in conjunction with the West Virginia Dental Association. We currently fund education in 34 counties and plan to expand to 40 counties by the end of calendar year 2005.

CDP provides supplies to organizations in all 55 counties of the state, including schools and Head Starts. These supplies include toothbrushes, supplies for fluoride rinse, and educational literature.

CDP has worked with community partners to establish clinics in Jackson, McDowell and Ritchie Counties.

CDP is seeking other interested community partners. We offer as much as 50% of the cost of a portable dental unit; and technical assistance on working with school systems, professional recruitment and revenue projections.

CDP has a portable dental unit (chair and equipment) on loan to the Marshall County Health Department for the purpose of performing services such as examinations and cleanings for Head Start recipients.

CDP has historically received funding (\$17,500) from the Preventive Health Services Block Grant which pays for sealants for those otherwise unable to afford them. This funding will not be available for FY 2006. In the most recent completed year, state FY 2004, 311 children received 1,095 sealants.

We have repeatedly heard that some children with special needs have problems finding a dentist to treat them, even those whose disability is relatively moderate. In addition, dentists have told us they need training to work effectively with this population. In response, CDP and Valley Health Systems (VHS) are exploring the possibility of creating a special needs clinic and training facility at the VHS/Westmoreland Clinic in Huntington.



In addition, the Infant, Child and Adolescent Health Division, of which CDP is a member project, now includes West Virginia's Children with Special Health Care Needs Program (CSHCN). This Program is responsible for coordinating the care of these children, regardless of coverage source. The organizational realignment will make it easier to give this issue additional emphasis in the future.

OHP publishes a directory of West Virginia dentists serving children. This directory indicates whether the dentist is willing to serve children with various coverage sources, including Medicaid and CHIP, and whether the dentist is accepting new patients. The directory has been distributed to HealthCheck (EPSDT) providers (over 460), school-based clinics, school health nurses and local health departments.

### Special Projects

#### 1) McDowell, Mercer and Wyoming Counties

CDP obtained additional federal funding from the Health Services and Resources Administration (HRSA) to start a school-based dental project in McDowell County. CDP also received continuation funding which will allow replication of the project in Mercer and Wyoming Counties if dental practitioners to perform the services can be identified.

This funding also allows for oral health education. All school children served receive a toothbrush, floss, paste and literature on oral hygiene.

#### 2) Oral Health Forum

OHP partnered with the West Virginia Head Start Association, the Region III Head Start Technical Assistance System, the Association of State and Territorial Dental Directors, the Oral Health Task Force and others to sponsor an Oral Health Forum in October, 2004. Many of the recommendations from the Forum describe activities OHP is currently involved in. Recommendations (worded verbatim from the Forum notes) from Forum participants are in italics with the OHP activity immediately afterward.

*Students will train the Pre-K staff and staff will train parent*

The OMCFH/Early Childhood Health Project is sponsoring trainings for child care providers on oral hygiene for children. These trainings will be conducted by dental professionals currently contracting with OMCFH to provide oral health education in other venues.

### *EPSDT requirements for Oral Screening/Exams/referrals and documentation*

The OMCFH/HealthCheck Program protocol requires a visual assessment of the oral cavity for all participating children. HealthCheck also requires medical practitioners to refer children for dental appointments by age 2 (lowered from the previous requirement of age 3). While HealthCheck has always informed medical providers of the need for dental referral, field representatives, known as Program Specialists, add emphasis about this need during semi-annual provider visits. This effort began in 2001. Since then, the percentage of Medicaid children receiving any dental service and the number receiving preventive dental services has increased steadily. For children aged 3 through 20 (the traditional years for referral to a dentist), those percentages were 42% and 35% respectively in 2003. The use of the dental resource directory is also to facilitate the referral process.

### *Educate teachers of dental care importance*

The OMCFH/Oral Health Program contracts with local dental professionals to provide oral health education in public schools in 34 counties. Teachers in the classrooms are in attendance during these sessions.

### *Mobile dental units*

The OMCFH/OHP has partnered with the DHHR/Bureau for Public Health/ Office of Community Health Systems/Division of Primary Care and local entities to fund portable dental units for use in schools, Head Starts and other locations in which fixed equipment would not be feasible.

Since the 1970's, there have been attempts to take health care services to those needing it, using specially equipped vans or trucks. It has not worked well in West Virginia and we can not recommend this as a strategy.

### *Collaboration with State DOE and WV Bureau for Public Health*

At this time, OMCFH is partnering with the West Virginia Children's Health Insurance Program, the DHHR/Bureau for Children and Families/Office of Early Care and Education and the West Virginia Department of Education to make the HealthCheck protocol the common protocol for all well-child exams for very young children (including compulsory pre-school screens). As stated above, the HealthCheck protocol reiterates the need for oral health screening and referral. If this is successful, the partnership will consider encouraging all medical providers to use this protocol for other age groups.

### *Education of parents on availability of existing transportation support*

Transportation support is available to children with Medicaid coverage. Families are informed of this benefit upon enrolling in Medicaid and when enrolling in HealthCheck.

### *Pursue funding to create transportation systems to support dental appointments, follow through*

While OHP is not the appropriate organizational unit to pursue funding for this purpose, the ICAH Division Director is a member of the Governor's Transportation Coordinating Council. The basic objective of the Council is to identify underutilized transportation resources and move those resources toward full use. This effort could create opportunities for transportation to dental appointments.

### *School Based dental/medical programs and health departments*

As stated above, OHP has worked with other partners to establish these clinics. OHP is seeking other interested partners. We offer as much as 50% of the cost of a portable dental unit; and technical assistance on working with school systems, professional recruitment and revenue/expense projections.

### *Collaborate with Right From The Start (before birth) on Oral Health Education*

OHP and Right From the Start (RFTS) are both housed within OMCFH. The two programs have collaborated on materials for pregnant women on the importance of prenatal dental care. In addition, OHP makes materials available to RFTS to educate participants about the importance of dental care for children and the prevention of baby bottle tooth decay.

### *Adult Services*

To comply with House Bill 3017, the Oral Health Improvement Act, all oral health programs in the Bureau for Public Health were consolidated. One of those programs had the objective of recruiting dentists to provide free services for medically-indigent, low-income adults, including those with disabilities. OHP reviewed the expenditures for this project and learned that only one sixth of the funds went for payment for dental services. Seeking to use more of the money toward that end, OHP took over administration of the project from an out of state contractor. The contractor refused to share information about dentists donating services, requiring OHP to rebuild the network and that effort continues. We have areas in which we need to recruit dentists; our greatest unmet need is currently in the southwest corner of the state. We also have areas in which we have a willing dentist but no patients.

### *Capacity to Address Needs:*

OHP continues to increase oral health education by expanding into new counties and eliminating inefficiencies. All oral health education expansions have occurred without benefit of new fiscal resources.

West Virginia has almost 800 licensed dentists. Most of those are practicing. Donated Dentistry has \$30,000 to serve approximately 70 people. If 10% of the practicing dentists would take one patient per year (assuming geographic distribution was somewhat even), we would be able to serve that number. Or, if all the practicing dentists would agree to take a turn in the rotation (again assuming a somewhat even geographic distribution), each practicing dentist in West Virginia would participate in Donated Dental once each ten years.

The Pre-Employment Project, funded with TANF resources by the Bureau for Children and Families and administered by the OMCFH was reinstated on December 1, 2004. This project pays for dental and vision services for those moving from welfare to work, serving approximately 2,000 people per year. We expect it to continue until June 30, 2006.

OHP has contracted with the preeminent oral cancer specialist in West Virginia, Jerry Bouquot, DDS, to offer education to dentists on early detection of oral cancers. While this expectation was established by House Bill 3017, we intend to continue this activity regardless of the future of that bill. The skill-building for dentists is vital considering West Virginia's high rate of tobacco usage.

### **MENTAL HEALTH**

Services for adults with serious mental illnesses and children with serious emotional disturbances are the responsibility of the Department of Health and Human Resources' (DHHR) Bureau of Behavioral Health and Health Facilities (BHHF), the only mental health care authority in West Virginia. The mission of BHHF is to improve the quality of life for all West Virginians with mental illnesses. The five divisions that comprise BHHF are the Division of Adult Mental Health, the Division of Children's Mental Health, the Division of Alcoholism and Drug Abuse, the Division of Mental Retardation/Developmental Disabilities and the Division of Data Integration & Security.

The tenet of the mental health delivery systems in the state is that all services should be focused on an evidence-based and culturally sensitive paradigm that centers on community and family involvement in the planning, development and delivery of services for adults with a serious mental illness and children with a serious emotional disturbance. This means that providers, consumers, families, and mental health organizations create a System of Care that provides an efficient and appropriate response to the evolution of needs that characterize the West Virginia family. This is in

keeping with the President's New Freedom Commission. Additionally, the BHHF has endorsed and promoted such evidence-based programming as assertive community treatment and supported employment. School-Based Mental Health, mediation and peer-run services are innovative services that are funded by the Bureau and offer viable options to conventional services.

According to the President's New Freedom Commission report, Achieving the Promise, research has demonstrated that mental health is key to overall physical health. Consequently, West Virginia has taken some steps toward integrating primary care and mental health care. On June 25, 2003 a survey commissioned by BHHF indicated that all the comprehensive behavioral health centers utilize a screening instrument to assess mental health problems. Over the subsequent years the State has encourage better access to a primary care physician by affording care coordination training and continuing education which will augment collaboration between behavioral health care and primary care.

Consistent with the SAMHSA priorities, Programs and Principle Matrix, West Virginia supports the development of programs that promotes life in the community by building resilience in our children and facilitating recovery in adults.

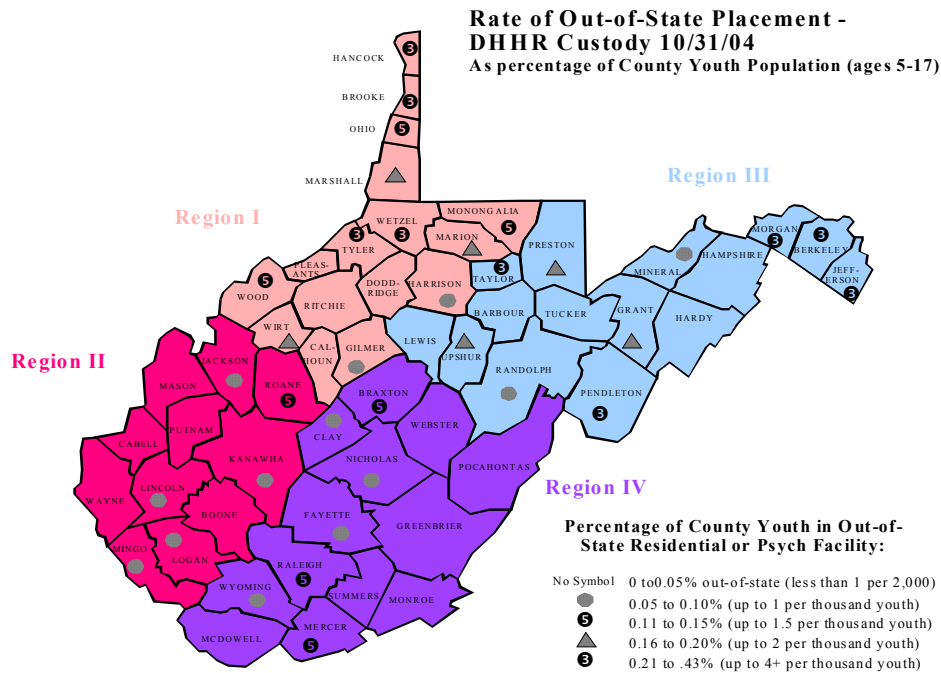
West Virginia is recognized by other states for:

- § Having a model system of care in Region II, which can be replicated throughout the State;
- § Utilizing creative approaches to community supports, utilizing consumers who are trained to provide services;
- Developing innovative and successful training of parents to serve as self- advocates for educational and mental health services;
- § Developing a range of community supports and community-based, out-patient crisis systems;
- § Developing a recovery-oriented training program in a community college to teach individuals to work in the community mental health system and;
- § Activities, including projects to bring children home from other states, creating jobs for people with disabilities, developing innovative transitional and permanent housing, and to creating leadership forums for teenagers.

Legislators were informed that, despite these accomplishments, West Virginia=s mental health system still has the following challenges:

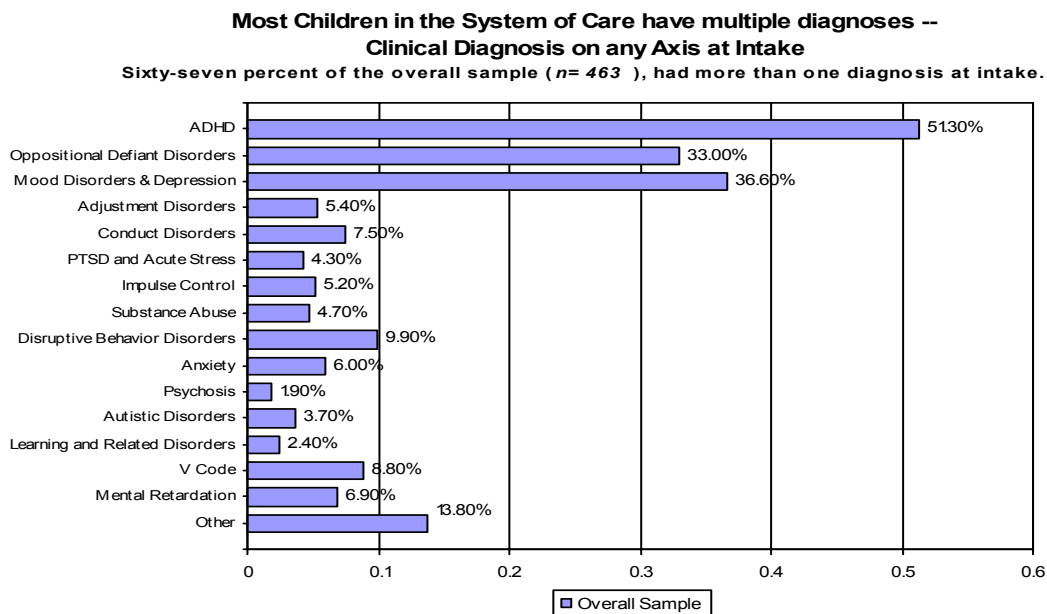
- § Children with emotional disturbances are sent out of state for services;
- § Families are split because of a perceived need to place children in State custody to access services;
- § Psychiatric hospitals are overcrowded, with millions of dollars expended on inpatient services for people who could and should be integrated into

- community programs;
- § A severe lack of safe, affordable housing for people with psychiatric disabilities;
- § Apathy about jobs for people with disabilities fosters an inappropriate and disproportionate reliance on expensive and restrictive treatment services.



Youth in DHHR Custody Out-of-State (Group Residential or Psychiatric Residential Treatment Facilities), Calculated as a percentage of the Region's 5 to 17 year olds.

**Source:** KidsCare and WV-DHHR Out-of-State Reports, U.S. Census Bureau County Quick Facts, 2003 population estimates.



### *Capacity to Address Needs:*

There are 914 licensed behavioral health beds serving the population of age two to eighteen in West Virginia and psychiatric beds for adults. Due to the poverty level in West Virginia, the 13% prevalence rate for developing a Serious Emotional Disorder applies to children and the 5.4% applies to adults. There are 1,395,313 adults age 18 and over and 440,984 children living in West Virginia. Based on the prevalence rates 75,347 adults and 57,328 children are at risk for, or have a serious and persistent mental illness or a serious emotional disturbance. In the State's population, 22.6% are high school graduates and 22.1% are college graduates. Of the population, 62.4% is age 18 to 64 years old with 59.6% of the population in the labor force. The median household income is at \$31,779 and the per capita income is at \$16,477. These statistics imply that in West Virginia mental health needs will continue to increase. This compels the Governor, the Department of Health and Human Resources, the Bureau for Behavioral Health and Health Facilities, and communities to actively search for best practices in restructuring mental health in West Virginia.

West Virginia is divided into 13 catchment areas for mental health planning and service delivery. Services are organized through catchment areas served by community behavioral health centers, which are contracted with the Bureau to provide the following core services to children and adults:

- Crisis services
- Linkages with inpatient and residential treatment services
- Medical, diagnostic
- Treatment
- Support services

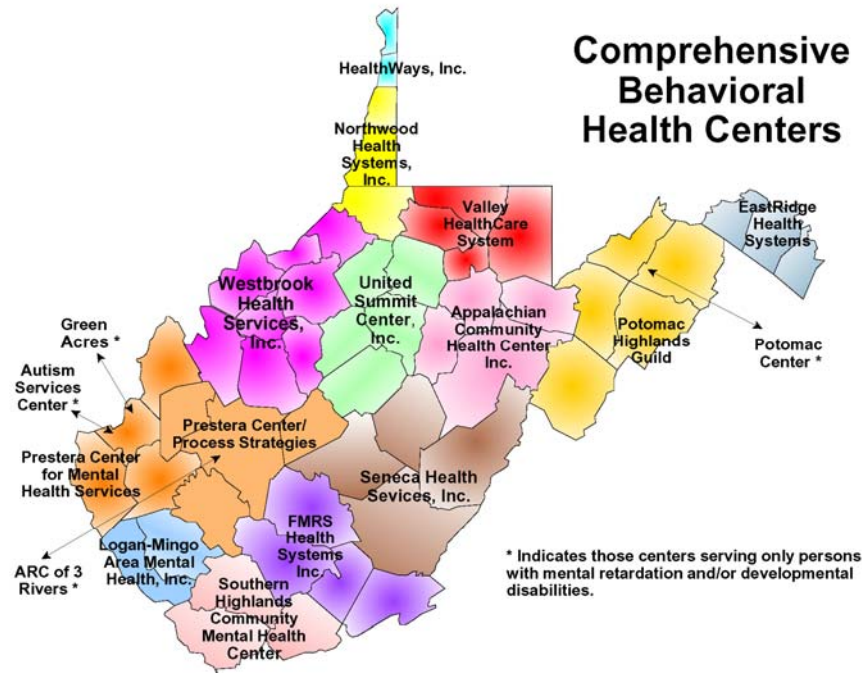
Comprehensive Behavioral Health Centers are nonprofit agencies, which provide community-based services and operate under the direction of a Board of Directors. The Board is generally chosen from the community stakeholders to whom the executive director reports. While other agencies may contract with the Bureau, the Regional Comprehensive Behavioral Health Center is the designated agency to provide basic community behavioral health care services and substance abuse services. In all areas of the State, the behavioral health centers collaborate with other community agencies and in some areas they are also a part of the regional Continuum of Care.

Case management, outreach, crisis-stabilization units, homeless outreach, substance abuse treatment and some limited supported housing is available to the community through interagency agreements for contract services. Typically, each of these centers operates a main office from which psychiatrists, physicians, psychologists and other mental health providers base their work. Rural areas may be served by satellite offices and, in some cases, audio/visual equipment may be used for outreach to remote areas.



Comprehensive Behavioral Health Centers serve children with Serious Emotional Disturbances and adults with Serious and Persistent Mental Illnesses. These centers provide care to families whose income is no more than 200% of the federal poverty level if they do not receive third party or targeted funds.

In addition to the thirteen community behavioral health centers, the Bureau for Health and Health Facilities funds eight community-based organizations to provide transitional living (halfway house services) for adults, two group homes for adolescents, and one freestanding residential treatment unit for adolescents.



A weakness of the system is the inadequacy of service delivery into the most rural parts of West Virginia. Vast distances often separate treatment facilities, and lack of transportation, challenging for mental health consumers even in metropolitan areas, is even more of a challenge in rural areas where public transportation services frequently do not exist. Of the 1,669 federally designated mental health professional shortage areas, more than 85% are rural, and such professional shortage problems are even more critical for children and older adults. It is problematic for clients to drive to a city an hour or two away for services more than once or twice a month. In some of the more rural counties in West Virginia, families may not have access to a vehicle that could transport them such a distance to seek mental health services, and for services such as therapy, weekly sessions are a requirement. In most cases, seeking services outside of their community is simply not an option.

Cost of service is a major barrier. Many of the newer psychoactive medications are very expensive. Although rural residents have comparable rates of insurance, they have less comprehensive coverage. Thus, of those people who have medical insurance, many may lack insurance coverage for psychotherapy – even if they can find a therapist in their area. In addition, treatment combining medication and psychotherapy is usually not an option for people in rural areas.

One unfortunate side effect of the ruling in the landmark case of *Olmstead vs. L.C.* (1999), where the U.S. Supreme Court ruled that unnecessary institutionalization of people with disabilities constitutes discrimination and therefore violates the Americans with Disabilities Act (ADA) is that many children who need mental health services will not receive them because their parents have no mental health insurance coverage and cannot afford services. Lack of quality inpatient care for severely mental ill people is a serious problem in rural areas. These patients often must obtain care in hospitals that are located far from where consultation is available.

Once discharged back into the community, there are limited psychosocial rehabilitation services available and thus patients are often re-hospitalized at a very high cost compared to outpatient care. This has forced parents to place their child in the child welfare or juvenile justice system in order to obtain services. Conscientious and devoted parents are faced with the anguishing decision of surrendering their parental rights and dismantling their family or denying a troubled child mental health services.

## **OBESITY**

Obesity has become an epidemic in West Virginia as well as across the nation over the past decade. There is increasing global incidence of cardiovascular disease, Type 2 diabetes, hypertension, certain cancers, and other obesity-related morbidities.

In December of 2002, a Summit on Obesity was held at the Embassy Suites in Charleston, WV. Key stakeholders throughout the state were invited to attend this Summit in the hopes that partnerships could be developed to work on carrying out strategies to reduce the burden of obesity in West Virginia. Objectives were:

- Statewide awareness about the increasing epidemic of obesity that is plaguing West Virginia and the nation;
- Commitment by key stakeholders to collaborate in a statewide partnership to address obesity issues;
- Identify and refine objectives and strategies to guide the development of an Obesity State Plan; and
- A “core” group of stakeholders will develop the West Virginia State Obesity Plan to guide West Virginia through the next two years in reaching Healthy People 2010 objectives.

A presentation was made by William Dietz, M.D., Ph.D., Division of Nutrition and Physical Activity, U.S. Centers for Disease Control and Prevention. According to his data, for the first time, in 1997, the category of > or = 20% was added to obesity trends among US adults, (30lbs overweight for a 5'4" woman). In 1998, West Virginia was one of the first states to meet this percentage and continues to be in this category through 2001 data.

#### West Virginia BRFSS, 1990 – 2000

The prevalence of obesity as measured by the Behavioral Risk Factor Surveillance System (BRFSS) has increased both nationally and statewide over the past decade, at an average annual rate of 5.9% in the U.S. and 5.2% in West Virginia, with the state's rate consistently higher than the national rate over the years. In 1990, the West Virginia rate was 15.0%, compared with the U.S. rate of 11.6%. By 2000, the West Virginia rate was 23.2%, compared with 20.1% for the nation as a whole. On the county level, obesity has increased in virtually all of West Virginia's 55 counties, with the highest prevalence found in the southern and western portions of the state, as well as the Eastern Panhandle. (see map)

Tracking the average weight in pounds for men and women from 1984 through 2000 has shown steady year-to-year increases for both sexes, with few exceptions over the 16-year period. In 1984, the average weight of adult males in WV was 177.2 pounds; by 2000, this had increased to 194.0 pounds. A similar increase was charted for the state's women, from an average weight of 142.0 pounds in 1984 to 154.9 pounds in 2000.

<b>Average Weight in Pounds for Men and Women aged 18+ WVBRFSS, 1984 - 2000</b>		
<b>Year</b>	<b>Men</b>	<b>Women</b>
1984	177.2	142.0
1985	176.6	143.4
1986	176.3	143.3
1987	178.6	142.3
1988	182.4	142.2
1989	179.1	144.7
1990	182.2	145.0
1991	184.2	146.8
1992	185.0	147.1
1993	184.1	150.0
1994	186.3	149.7
1995	185.8	150.8
1996	186.9	153.1
1997	188.8	152.6
1998	191.0	154.2
1999	193.3	157.2
2000	194.0	154.9

1999 Estimated U.S. Prevalence - 19.4%

1997-2001 WV Average - 24.2%  
(Significantly Higher)

## Prevalence of Obesity

West Virginia Behavioral Risk Factor Survey  
1997-2001 by County  
Compared to 1999 Estimated U.S. Prevalence

Legend:

- Significantly Higher than U.S. Prevalence
- Higher than U.S. Prevalence but not Significant
- Lower than U.S. Prevalence but not Significant
- Significantly Lower than U.S. Prevalence

Graphics by Health Statistics Center

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noted for those students who had tried to lose weight at some time during the 30 days prior to the survey, 57.8% of females vs. 30.2% of males. Only one in five students ate five or more servings of fruits and vegetables each day (24.6%) or drank at least three glasses of milk (18.7%).

Eighty-nine percent (89.4%) of male high school students reported during the 2001 YRBS survey that they participated in vigorous or moderate physical activity, compared with 93.1% of the female students. Fifty-eight percent (57.8%) of males and 42.2% of females had participated in strengthening exercises. On the negative side, 37.7% of males and 32.3% of females watched three or more hours of television on an average school day. Little difference was noted between state students and the national median in terms of activity and TV watching. Only 20.6% of West Virginia high school students were enrolled in physical education (PE) class at the time of the survey, 19.1% of males and 21.6% of females. Nineteen percent of males and 21.6% of females attended PE classes daily. Of those students enrolled in PE, 72.7% of males and 79.2% of females reported exercising at least 20 minutes during an average class. Overall, over half (55%) of the students had played on a sports team during the 12 months preceding the survey, 58.8% of males and 52.2% of females.

#### *Capacity to Address Needs:*

West Virginia has set the following 2010 Healthy People Obesity Objectives for children and adolescents as follows:

- 19.6 Increase the proportion of adolescents who consume breakfast daily by 5% from baseline. (Baseline data available in 2003)
- 19.7 Increase the proportion of adolescents who consume at least five servings of fruits and vegetables per day by 5% from baseline. (Baseline: 20.4% in 1999)
- 19.8 Increase the proportion of adolescents who meet dietary recommendations for calcium by 55 from baseline. (Baseline data available in 2003)
- 19.9 Increase the proportion of adolescents who consume less than 10% total calories from saturated fat by 5% from baseline. (Baseline data available in 2003)
- 19.10 Reduce the proportion of children and adolescents who are overweight or obese by 5% from baseline. Overweight or obese is defined as equal to or above the gender-and age-specific 95<sup>th</sup> percentile of BMI from the revised NCHS/CDC growth charts. (Baseline: 23% in 1998)
- 19.11 At a minimum, maintain current standards for Nutrition Education in school (Grades k-12)

- 22.3 Increase the proportion of WV's public and private elementary, middle/junior high, and senior high schools that provide daily lifetime fitness enhancing activities, including quality daily physical education (K-12) and recess (K-5), for all students during school hours. (Baseline for Overall Average of all schools providing daily Physical Education combined: 13 percent in 2002. Of the elementary schools surveyed, 94.3 percent offer daily recess and 5.2 percent do not. Of the elementary schools that offer recess, the average number of minutes per day students have recess is 24.1 minutes).  
Data Source: WV Department Of Education (WVDOE), Office of Healthy Schools (OHS), SHEP Survey
- 22.4 Increase to 35% the proportion of adolescents who engaged in moderate physical activity for at least 30 minutes on five or more of the previous seven days. (Baseline: 25.4% in 1999). Data Source: WVDOE, OHS, West Virginia Youth Risk Behavior Survey
- 22.5 Increase the proportion of WV's public elementary, middle/junior high, and senior high schools that provide access to their outdoor and indoor physical activity spaces and facilities for young people and adults outside of normal school hours (i.e., before and after the school day, on weekends, and during summer and other vacations). (Baseline: The percentage of WV schools that provide access to indoor facilities in 2002 is 42.3 percent. The percentage of WV schools that provide access to outdoor facilities in 2002 is 80.7 percent). Data Source: WVDOE, OHS, SHEP Survey

The West Virginia Coalition for Physical Activity and the West Virginia Nutrition and Chronic Disease Coalition were both established in the early 1990s to address the state's Healthy People 2000 and 2010 objectives. Both are facilitated by WVBPH's Cardiovascular Health Program, which drew together many agencies and individuals to (1) select the WV Healthy People 2010 Objectives and (2) subsequently develop strategies to meet these objectives.

The WV Coalition for Physical Activity has several state and local level representatives from higher education, WV Department of Transportation, WV Division of Tourism, WV Trails Coalition, school health, and nonprofit associations among its membership. The coalition's efforts currently center on creating walkable communities and increasing opportunities for youth to be more active during school hours. The WV Coalition for Physical Activity will continue to address the issues of obesity prevention as they relate to physical activity.

The WV Nutrition and Chronic Disease Coalition membership includes representatives from the Public Employees Insurance Agency, Highland Hospital, West Virginia University, WVBPH's Office of Nutrition Services, WV Coalition on Food and Nutrition, American Cancer Society, and WV Dairy Council, among others. Its current

priority areas address the USDA's 5-A-Day program to increase consumption of fruit and vegetables and healthy portion sizes. The WV Nutrition and Chronic Disease Coalition will continue to focus on the issues of obesity prevention relating to nutrition.

Priority populations for the Obesity Prevention Program were identified based on data from *The Burden of Cardiovascular Disease in West Virginia*, a 2001 report issued by the WV Bureau for Public Health (98). These populations are underserved youth, seniors, racial and ethnic minorities, and women 18 to 34 years of age.

The physical activity, nutrition, and priority populations coordinators, all located within the WVBPH's Division of Health Promotion and Chronic Disease, are organizing efforts in their specific areas within existing chronic disease programs. The coordinators work through the Bureau's internal programs and with other outside agencies, organizations, and community members to best determine how to improve physical activity and nutrition by using policy and environment approaches.

The state-supported Community-Based Initiatives Grants Program funds community projects that address the West Virginia Healthy People 2010 Objectives for Physical Activity and Fitness and Nutrition and Overweight by using policy and environment strategies. Funding priority is also given when priority populations are targeted. This program, in conjunction with the regional Health Promotion Specialists Network, has helped build the infrastructure necessary for successful community-based programs.

Regional and/or county health networks can be mobilized to address obesity prevention in a collaborative fashion. Many of these networks are already established, including the Adolescent Health Initiative, the cancer information specialists, and the WVU Extension Service. Involving nontraditional partners such as city councils, regional planning development councils, and economic development agencies can build on these efforts.

Young people need to build healthy bodies and establish healthy lifestyles. Yet the school environment is less supportive of health and has less access to healthful choices than ever before. The WVBPH has partnered with the WV Department of Education's Office of Healthy Schools to address the WV Healthy People 2010 Objectives. Collaborative projects have included collecting data to establish baselines, completing inventories, developing Walk to School initiatives, and training principals.

Several other youth programs are currently being implemented, such as Coronary Artery Reduction and Detection In Appalachian Communities (CARDIAC), Healthy Hearts Internet Module, Helping Educators Attack CVD Risk Factors Together (HEART), and Choosy Kids. School and community-based programs are vital to the improvement of youth behaviors in physical activity and nutrition.

## **ASTHMA**

Asthma is a chronic lung disease that affects many West Virginians. This disease is characterized by recurrent respiratory symptoms such as wheezing, breathlessness, chest tightness, coughing, and variable airflow obstruction that is reversible spontaneously or with treatment.

The 2000 Behavioral Risk Factor Surveillance System (BRFSS) reported that the prevalence of lifetime asthma among adults in West Virginia was 11.7%, which exceeds the national figure of 10.5%. In the year 2001, the prevalence in West Virginia increased to 12.5%, representing approximately 174,835 West Virginia adults. The prevalence of current asthma among adults in West Virginia was 8.5% in 2000 and increased to 9.3% in 2001 (approximately 130,118 West Virginia adults). The state now ranks 6th highest in the nation in lifetime asthma prevalence, and 5th highest in current asthma prevalence. The lifetime asthma rate for West Virginia adults was greatest among those aged 18-24 years, those who had not graduated from high school, and those with an annual income of less than \$15,000.

Data from the 2002 West Virginia Youth Tobacco Survey (WVYTS) indicate that 23.2% of middle school students and 21.1 % of high school students (an estimated 32,757 total) reported that they have at some point been diagnosed with asthma by a doctor. Of those students who indicated that they have been diagnosed with asthma, 14,099 reported that they have had at least one attack within the past year. This is especially concerning since having attacks indicates poorly controlled asthma. Among those students who had an attack within the last year, over 20% reported that they missed 11 or more school days in the past year due to their asthma. Data from the WVYTS also indicate that lifetime asthma prevalence and asthma attack prevalence were both significantly higher among current smokers in middle schools compared with nonsmokers.

Data from the West Virginia Health Care Authority (WVHCA) show that, from 1995-2001, the hospitalization rates for asthma in West Virginia were lower than those in the United States as measured by the National Hospital Discharge Survey (NHDS). During the same period, the total hospital charges in West Virginia for discharges with a primary diagnosis of asthma averaged approximately \$10.3 million per year.

West Virginia's vital statistics database indicates that, from 1991 through 2000, about 35 West Virginians died yearly from asthma (asthma listed as the primary cause of death). This averages about two persons per 100,000 population per year.

During calendar year 1999, about 20.9 per 1,000 recipients of West Virginia Medicaid had at least one medical claim (whether for inpatient, outpatient, or emergency room treatment) with a primary diagnosis of asthma. The rate among blacks was 25% higher than that among whites; in addition, the rate was also higher in



females compared with males and in the 21-64 year age group compared with other age groups. In the same year, West Virginia Medicaid incurred \$2,690,777 for hospitalizations, \$589,878 for outpatient visits, and \$236,857 for emergency department visits with a primary diagnosis of asthma.

West Virginia's Workers' Compensation claims data indicate that during calendar years 1997 -2001 there were 245 compensated cases of occupational asthma, with the maximum number of cases in services, manufacturing, and mining, oil, and natural gas industries. During the same period, over \$4.3 million were paid for medical compensation and \$2.7 million for indemnity (lost wages and disability) compensation (ongoing costs).

#### *Capacity to Address Needs:*

The West Virginia Asthma Education and Prevention Program (WV -AEPP) was created by the West Virginia Department of Health and Human Resources through a grant from the Centers for Disease Control and Prevention. The WV-AEPP is located within the Bureau for Public Health's Division of Health Promotion and Chronic Disease (Chronic Disease Section).

The mission of the WV-AEPP is to develop, implement, and evaluate a statewide strategic asthma plan in the ultimate interest of reducing the health and economic consequences attributed to asthma in West Virginia. The WV-AEPP aspires to highlight asthma as a priority health concern and to reduce suffering, disability, death, and economic costs related to asthma by:

- Developing a broad-based statewide asthma planning, implementation, and evaluation group.
- Analyzing existing data sources to determine the prevalence, cost, and burden of asthma.
- Developing a statewide asthma surveillance system.
- Publishing and disseminating a report on asthma.
- Developing a statewide plan and recommendations to address asthma.
- Developing and implementing asthma interventions.

This report constitutes one important element in our initiative, and will be utilized in the development of the state's strategic plan to address asthma.

## **INJURIES**

West Virginia Injury Prevention Coalition (WVIPC) is an association of health care professionals, policy makers, educators, researchers, public health and injury specialists, law enforcement officials, and consumers, all concerned West Virginian's dedicated to better understand and reduce the health burden of injury. In association

with the West Virginia University Center for Rural Emergency Medicine, the Coalition produces an injury study every 5 years.

Key Findings, 2000 study:

- Injuries account for about 6% of all deaths.
- Men are nearly twice as likely to die of an injury compared to women.
- Unintentional injury is the leading cause of deaths for persons 1 - 34 years of age.
- The seat belt usage rate in 1999-2000 was 50% compared to 71% nationally.
- Two-thirds (2/3) of the 2000 motor vehicle related fatalities were males, 11% were under age 18, 17% were 60 or older, and 37% involved alcohol.

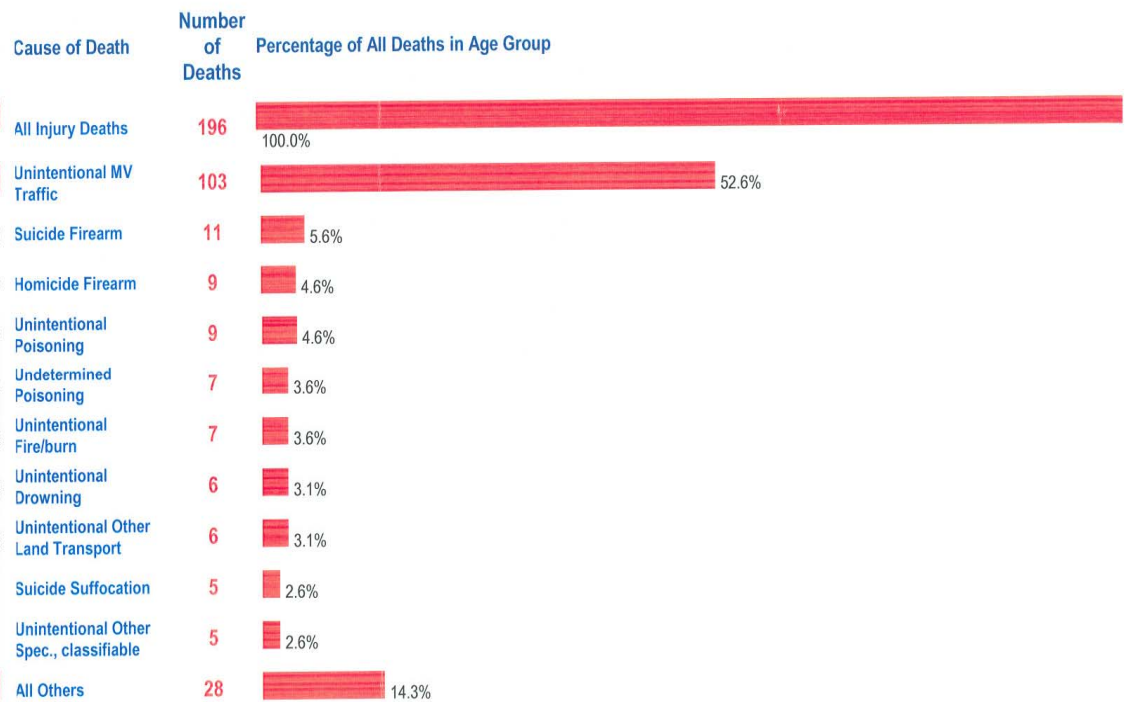
According to the WV Health Statistics Center in 2003, there were 175 children and young adults 0-24 years old who died from an accident. Of the 273 deaths, ages 15-24, 141 or (51.6%) were caused from accidents. Of the 141 accidental deaths, 91 or (65%) were caused from motor vehicle injuries. In the 15-19 age group 60 or (55%) of the 109 deaths were caused from accidents and of the 60 accidents, 47 or (78%) were caused from motor vehicle injuries.

Every year in West Virginia, about 1200 people die from injuries, another 17,250 are hospitalized and as many as 225,000 are treated in hospital emergency departments. From a historical perspective, injuries have often been referred to as "accidents", thus implying that they could not have been prevented. Most injury events, however, are either preventable or could easily have resulted in less severe injuries. The science of injury control is fairly new to the nation, and public health professionals are just beginning to comprehensively address the topic. Many strategies exist which can help us prevent or survive an injury. Some of these strategies are in the form of laws or safety regulations, while others protect us through better product design and safety engineering. **However, our personal attitude and behaviors are the most vital components of successful injury prevention.**

### 10 Leading Causes of Injury Deaths, West Virginia

2001, All Races, Both Sexes

Ages: 1-24



Produced By: Office of Statistics and Programming, National Center for Injury Prevention and Control, CDC  
 Data Source: National Center for Health Statistics (NCHS) Vital Statistics System

**10 Leading Causes of Death, West Virginia  
2001, All Races, Both Sexes**

Rank	Age Groups											
	<1	1-4	5-9	10-14	15-19	20-24	25-34	35-44	45-54	55-64	65+	All Ages
1	Short Gestation 28	Unintentional Injury 12	Unintentional Injury 8	Unintentional Injury 8	Unintentional Injury 53	Unintentional Injury 66	Unintentional Injury 112	Unintentional Injury 148	Malignant Neoplasms 393	Malignant Neoplasms 794	Heart Disease 5,221	Heart Disease 6,325
2	Congenital Anomalies 26	Congenital Anomalies 4	Anemias 1	Malignant Neoplasms 3	Suicide 7	Suicide 13	Suicide 42	Malignant Neoplasms 138	Heart Disease 359	Heart Disease 606	Malignant Neoplasms 3,329	Malignant Neoplasms 4,685
3	SIDS 23	Heart Disease 2	Congenital Anomalies 1	Homicide 2	Homicide 6	Homicide 7	Malignant Neoplasms 22	Heart Disease 111	Unintentional Injury 117	Chronic Low Respiratory Disease 127	Cerebro-vascular 1,155	Chronic Low Respiratory Disease 1,273
4	Maternal Pregnancy Comp. 14	Homicide 2	Heart Disease 1	Congenital Anomalies 1	Malignant Neoplasms 5	Congenital Anomalies 4	Heart Disease 18	Suicide 60	Suicide 67	Diabetes Mellitus 106	Chronic Low Respiratory Disease 1,094	Cerebro-vascular 1,272
5	Placenta Cord Membranes 6	Septicemia 2	Suicide 1	Influenza & Pneumonia 1	Meningo-coccal Infection 2	Heart Disease 4	Homicide 9	Diabetes Mellitus 29	Diabetes Mellitus 55	Unintentional Injury 62	Diabetes Mellitus 608	Unintentional Injury 834
6	Atelectasis 5	Atherosclerosis 1			Congenital Anomalies 1	Six Tied 1	Congenital Anomalies 7	Liver Disease 29	Liver Disease 48	Cerebro-vascular 61	Influenza & Pneumonia 432	Diabetes Mellitus 802
7	Unintentional Injury 5	Benign Neoplasms 1			Heart Disease 1	Six Tied 1	Cerebro-vascular 5	Cerebro-vascular 15	Chronic Low Respiratory Disease 45	Nephritis 36	Alzheimer's Disease 394	Influenza & Pneumonia 483
8	Chronic Respiratory Disease 4	Diabetes Mellitus 1			Pneumonia 1	Six Tied 1	Septicemia 5	HIV 15	Cerebro-vascular 35	Liver Disease 35	Nephritis 336	Alzheimer's Disease 398
9	Neonatal Hemorrhage 4					Six Tied 1	HIV 4	Homicide 14	Nephritis 17	Suicide 31	Septicemia 272	Nephritis 391
10	Two Tied 3					Six Tied 1	Two Tied 3	Two Tied 7	Septicemia 15	Septicemia 31	Unintentional Injury 243	Septicemia 334

Produced By: Office of Statistics and Programming, National Center for Injury Prevention and Control, CDC  
Data Source: National Center for Health Statistics (NCHS) Vital Statistics System.

### *Capacity to Address Needs:*

Injury prevention is a priority of the State health plan. Sixteen (16) of the 212 objectives, outlined in Healthy People 2010, are related to unintentional injury control and violence prevention.

The State of West Virginia has, for a long time, had a law that requires the use of child restraints, a car seat, until a child reaches 40 pounds or 4 years of age. However, based on the National Highway Safety Administration's recommendations, West Virginia lawmakers, in the 2005 legislative session, passed a bill requiring federally approved child safety seats or boosters for children up to the age of 8 years. The director of the West Virginia Governor's Highway Safety Program advocated for this legislative change, stating "child safety seats have been proven to effectively reduce the risk of fatalities and injuries. Booster seats, in particular, help the seat belt to fit the child better once they grow out of a harness system. A better fit means a greater chance of survival or little to no injury in a car crash." West Virginia now joins the ranks of 32 other states that are requiring some type of safety or booster seat for children up to the age of 8.

MCFH targets medical practitioners serving children as a vehicle for distribution of injury prevention information for parents. Materials distributed are generally one page, and address health-related behaviors such as providing constant supervision when children are in the bathtub, including periodic drills and establishing escape plans in the event of fire, and not bringing infants into bed with them. The distribution of anticipatory guidance (health education information) is routinely distributed by the Pediatric Program Specialists, who serve as liaison to the medical community. Copies of injury prevention materials are also shared with childcare agencies including Head Start.

The OMCFH in collaboration with the Domestic Violence Coalition continues to produce and distribute information on date rape, bullying etc. There are also training opportunities offered to address prevention routinely provided by the Adolescent Health Coordinators which includes use of bike helmets, mouth guard use when engaged in sport activities etc. See earlier reports in Block Grant related to adolescent health.

**C. STATE MCH POPULATION GROUP:  
CHILDREN WITH  
SPECIAL HEALTH CARE NEEDS**

### **C. STATE MCH POPULATION GROUP: CHILDREN WITH SPECIAL HEALTH CARE NEEDS**

A broad assessment was completed on the following areas:

- **INTRODUCTION/DIRECT SERVICES**
- **NATIONAL SURVEY**
- **EARLY IDENTIFICATION SERVICES**
  - Systems Point of Entry
  - Birth To Three/Part C/IDEA
  - Emergency Preparedness For Children With Special Needs
- **ACCESS TO QUALITY HEALTH CARE**
  - Nutrition Services
  - Adequate Insurance
- **PARENT/FAMILY INVOLVEMENT**
- **SPECIAL EDUCATION**
  - WV IDEA Self-Assessment Process
  - Educational Efforts for the Deaf and Hard of Hearing Population
- **TRANSITION SERVICES INCLUDING SELF-ADVOCACY AND SKILL DEVELOPMENT**
  - Self-Determination
  - Mountaineer Camp

#### **INTRODUCTION/DIRECT SERVICES**

The OMC FH administers the CSHCN Program. The Program serves medically indigent children, with Title V acting as the payor and children who are Medicaid or CHIP beneficiaries with qualifying medical conditions. West Virginia does not utilize the HRSA/MCHB definition of CSHCN because we do not have the fiscal resources to serve all the children who would then meet the diagnostic guidelines.

The CSHCN offers health and care coordination services to children and their families, if the child has a program covered medical diagnosis. A master listing of covered services is a part of the needs assessment document (See attachment 1).

Ever increasing cost of medical care, the varying availability of medical specialists, and the static number of staff (nurses and social workers) to provide medical and ancillary care to children with special health care needs has precipitated the above decision. The effects of this administrative decision is also echoed in our data reports, since the MCH Bureau evaluates the number of SSI beneficiaries, by state, participating in CSHCN. West Virginia's SSI beneficiaries under the age of 16 years largely do not have a diagnosis that is covered by the CSHCN, as evidenced by the graph below:

## SSI Beneficiaries/Child by Age for West Virginia

West Virginia	Total	Age			Amount of Payments (in Thousands)
		Under 5	5-12	13-17	
Total	7,706	1,080	3,714	2,912	\$3,909
Diagnosis Available	7,244				
Infectious and Parasitic Diseases	8	1	5	2	3
Neoplasms	71	12	45	14	33
Endocrine, Nutritional, and Metabolic Diseases	92	23	38	31	43
Diseases of Blood and Blood-forming Organs	18	2	11	5	9
Mental Disorders (Other than Mental Retardation)	2,280	150	1,308	822	1,211
Mental Retardation	2,376	22	1,026	1,328	1,154
Diseases of:					
Nervous System and Sense Organs	793	136	412	245	393
Circulatory System	40	10	22	8	23
Respiratory System	144	46	73	25	70
Digestive System	34	19	7	8	15
Genitourinary System	26	5	14	7	13
Skin and Subcutaneous Tissue	7	2	3	2	3
Musculoskeletal System	87	16	44	27	41
Congenital Anomalies	333	141	139	53	164
Injuries	28	3	13	12	13
Other	907	381	322	204	473

Source: Social Security Administration

The WV Children with Special Health Care Needs Program continued a strong commitment to family-centered, community-based, direct services during calendar year 2004. During calendar year 2004, 6,856 children and youth were served through a network of 48 CSHCN community-based specialty care clinics, and through private specialty physicians' offices state wide. Of the 3,447 visits provided through the clinic system, 535 visits were for initial diagnostic evaluations. During this period, 81.99% of children participating in CSHCN were also Medicaid beneficiaries. This increase over the year 2003 percentage is attributed to the continuing commitment of CSHCN to assist families in obtaining health care financing by assisting with SSI and/or CHIP/Medicaid applications. As of December 2003, there were 8,219 children in WV under the age of 18 receiving SSI benefits. During CY 2004, 1,459 children ages 0-18 received both SSI and CSHCN benefits. This indicates that the CSHCN program served 19.07% of WV children under the age of 18 who receive SSI benefits.

### *Capacity to Address Needs:*

Multi-disciplinary teams provide care-planning and care-coordination to CSHCN program participants. The multi-disciplinary team includes the child/parent, physicians, nurses, social workers, therapists, school personnel, vendors and community services who are providing care for the child. Team members, led by the CSHCN nurse and/or social worker, collaborate with the child/family in developing an appropriate, comprehensive care plan for the child. During CY 2004, 1,755 Patient Care Plans were



completed to assure a continuum of comprehensive medical care and transition to adult care as appropriate. This brought the total number of Patient Care Plans in place for enrolled CSHCN recipients to 3,505.

During FY 2004, each regional care coordination team began holding weekly planning meetings to better coordinate their work and to assure responsibilities for tasks within the group. This assists with setting and meeting work priorities, and serves as an opportunity for review of program policies and procedures.

Efforts are made to coordinate the CSHCN specialty care with the child's medical home, and to keep the primary care physician informed of treatment plans. CSHCN strives to provide service in a manner that is accessible, family-centered, and coordinated. CSHCN coverage is provided throughout the state either in a specialty care physician's office or in face to face contacts at a CSHCN clinic site closest to the child's home. Medical transportation costs for appointments are reimbursed at the DHHR Medicaid established rate. The child and the principal care givers are informed of treatment options and involved in development of the Patient Care Plan for the child. Services are continued until the child's 21<sup>st</sup> birthday with transition services available to prepare for adult medical care. Through the Patient/Family Assessment and Patient Care Plan development process, families are linked to medical, educational, and community-based services.

To ascertain the appropriateness of specialty medical care and application of program policy, the CSHCN Medical Associates reviewed case records of enrolled children. The CSHCN Orthopedic Associate reviewed over 1000 records of children being followed for orthopedic care. Similarly, the CSHCN Otolaryngology Associate reviewed 80 records of children followed in the Charleston Plastic Surgery Clinic. The Pediatric Associate reviewed 90 records of children receiving nutritional supplements. During the coming year, the CSHCN Otolaryngology Associate will review the records of all children receiving hearing and Ear, Nose, and Throat services.

In June 2004, the CSHCN Orthopedic Associate held an assessment clinic to expedite orthopedic evaluations for applicants for CSHCN services. This clinic served applicants from the counties of Kanawha, Putnam, Clay and other areas in central West Virginia.

The following model represents the WV OMCfH Continuum of Care for CSHCN and their families:

### Continuum of Services for CSHCN and Their Families



WVDHHR/BPH/OMCFH/CAH/CSHCN/03-05

## **NATIONAL SURVEY**

The National Survey of Children with Special Health Care Needs, sponsored by the MCHB, in 2001 produced national and state estimates of prevalence and impact of special health care needs among children 0–17 years of age. Following are the results for West Virginia:

### **WEST VIRGINIA**

**NOTE:** All Statistics are based on parental reports.

**Estimate of Number of Self-Reported Children with Special Health Care Needs:  
66,201**

#### **PREVALENCE STATISTICS**

<b>Child-Level Prevalence:</b>	<b>State %</b>	<b>National %</b>
Percent of Children with Special Health Care Needs	16.7	12.8
<b>Prevalence By Age:</b>	<b>State %</b>	<b>National %</b>
Children 0-5 years of age	9.0	7.8
Children 6-11 years of age	20.7	14.6
Children 12-17 years of age	19.8	15.8
<b>Prevalence by Sex:</b>	<b>State %</b>	<b>National %</b>
Male	18.7	15.0
Female	14.7	10.5
<b>Prevalence By Poverty Level:</b>	<b>State %</b>	<b>National %</b>
0%-99% FPL	24.9	13.6
100%-199% FPL	18.4	13.6
200%-399% FPL	12.7	12.8
400% FPL or greater	13.7	13.6
<b>Prevalence By Race/Ethnicity:</b>	<b>State %</b>	<b>National %</b>
Hispanic	16.6	8.6
White (Non-Hispanic)	16.5	14.2
Black (Non-Hispanic)	14.0	13.0
Asian (Non-Hispanic)	----	4.4
Native American/Alaskan Native (Non-Hispanic)	----	16.6
Native Hawaiian/Pacific Islander (Non-Hispanic)	----	9.6

---- Due to the small size of this group in the State population, data have been suppressed to protect respondents' confidentiality.

## INDICATOR

<b>Child Health:</b>	<b>State %</b>	<b>National %</b>
Percent of Children with Special Health Care Needs whose conditions affect their activities usually, always, or a great deal.	19.1	23.2
Percent of Children with Special Health Care Needs with 11 or more days of school absences due to illness.	22.0	15.8
<b>Health Insurance Coverage:</b>	<b>State %</b>	<b>National %</b>
Percent of Children with Special Health Care Needs without insurance at some point in the past year.	16.3	11.6
Percent of Children with Special Health Care Needs currently uninsured.	8.4	5.2
Percent of currently insured Children with Special Health Care needs with insurance that is not adequate.	30.6	33.5
<b>Access to Care:</b>	<b>State %</b>	<b>National %</b>
Percent of Children with Special Health Care Needs with any unmet need for specific health care services.	14.2	17.7
Percent of Children with Special Health Care Needs with any unmet need for family support services.	2.8	5.1
Percent of Children with Special Health Care Needs needing specialty care who had difficulty getting a referral.	23.1	21.9
Percent of Children with Special Health Care Needs without a usual source of care (or who rely on the emergency room).	6.0	9.3
Percent of Children with Special Health Care Needs without a personal doctor or nurse.	11.9	11.0
<b>Family Centered Care:</b>	<b>State %</b>	<b>National %</b>
Percent of Children with Special Health Care Needs without family centered care.	32.3	33.5
<b>Impact on Family:</b>	<b>State %</b>	<b>National %</b>
Percent of Children with Special Health Care Needs whose families pay \$1,000 or more in medical expenses per year.	9.6	11.2
Percent of Children with Special Health Care Needs whose condition caused financial problems for the family.	22.0	20.9
Percent of Children with Special Health Care Needs whose families spend 11 or more hours per week providing or coordinating care.	19.4	13.5
Percent of Children with Special Health Care Needs whose condition affected the employment of family members.	28.4	29.9

The above statistics set the stage for much of the needs assessment of the children with special needs in West Virginia.

## **EARLY IDENTIFICATION SERVICES**

### **Systems Point of Entry**

As discussed on page 17, West Virginia has established an early identification system that has proven to be effective in identifying infants and children in need of service. At the core of the identification system is the System Point of Entry toll-free line responder service, which works closely with CSHCN.

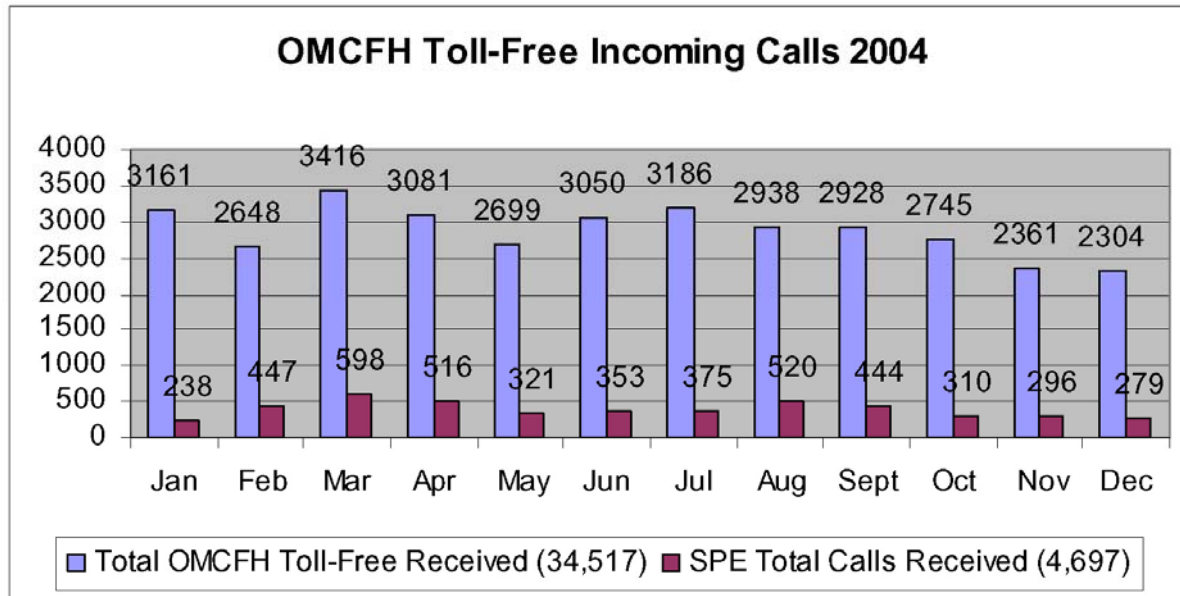
The OMCFH's Systems Point of Entry (SPE), which includes the toll-free lines, responds to families that do not have Medicaid, CHIP or private insurance coverage for health services. Staff from the Systems Point of Entry assist families in making applications for government financed health service. Some families do not qualify for government assistance. These families receive special case management services linking them to care offered by private agencies. This may include SPE contacting a hospital to encourage the write-off of a bill or arranging for the family to be seen by a community health center at a reduced rate.

Information about a child's primary care provider (medical home) is gathered by SPE during initial intake, and by CSHCN staff each time a child presents for service. During CY 2004, 3,724 children who received CSHCN services had an identified primary care practitioner. This represents 81.72% of the children enrolled or in pending status with CSHCN. SPE service coordinators link children, without an identified primary care practitioner, to the HealthCheck Program and to local sources for medical care. All children receiving benefits through the WV Medicaid Program are assigned a primary care physician as a part of their enrollment in Medicaid Managed Care.

During Calendar Year 2004, Systems Point of Entry provided the following activities:

1. 790 requests for referral services provided:
  - 402 families identified by the Social Security Administration as approved for Supplemental Security Income (SSI) were offered additional referral services
  - 89 requests received from OMCFH Children's Reportable Disease, Newborn Metabolic, and Lead Screening Programs
  - 299 families of children identified on the Birth Registry as having congenital problems received OMCFH program information
2. 1,583 applications or informational materials provided:
  - 596 Specialty Care Intake Forms (SCIF) for CSHCN applications
  - 42 Children's Health Insurance Program (CHIP) applications
  - 17 OBRA applications for Medicaid coverage for pregnancy
  - 928 brochures/pamphlets concerning resources for services

3. 4,697 telephone inquiries received by the toll-free responder.



*Capacity to Address Needs:*

The OMC FH Quality Assurance and Monitoring Unit reviewed 309 of the total customer call-in contacts received by Systems Point of Entry for consumer satisfaction. Approximately 20% of these calls were from families of children with special health care needs. Public response to SPE telephone referral and assistance operation continues to be completely positive. Those contacted stated that they were pleased with the way they were treated. None indicated dissatisfaction with the services and guidance received.

Effective January 15, 2004, the Systems Point of Entry Unit began using an electronic format system for collecting information on calls received on the toll-free lines. This eliminated the manual record keeping system. This served to increase the efficiency of record keeping as well as improving access of the OMC FH Quality Assurance and Monitoring Unit to SPE recordings for monitoring of customer satisfaction.

## **Birth to Three (Part C/IDEA)**

The goal of Birth to Three is the early identification of infants and toddlers with developmental disabilities in order to allow services to begin quickly.

Results from AAP survey of pediatricians in 2002 on behalf of the Office of Special Education Programs, US Department of Education as follows:

### **Referral to Early Intervention**

86% have been referred to Early Intervention (EI).  
92% say EI helps maximize child development.  
95% say parental concern is a referral consideration.  
77% know family income doesn't matter.

### **Barriers to EI Referral**

30% do not receive evaluation results.  
54% don't hear when the family is no longer involved with EI.  
61% do not receive notification of EI inability to contact family.  
49% do not receive Individualized Family Service Plan and progress reports.

### **AAP Survey Recommendations**

Preprinted standard referral form (51%).  
Toll-free number  
Give M.D.'s more information about EI.  
Improve communication from EI, especially confirmation of referral receipt.  
Make local contact from EI known in the community.

### ***Capacity to Address Needs:***

### **West Virginia Response**

- Identify 4 M.D. champions to promote Early Intervention at AAP meetings, AAFP.
- Regional Administrative Units (RAU) in each of the 8 areas of West Virginia have responsibility for Child Find on behalf of the Lead Agency for Title V – MCFH. As a part of this assignment, RAU staff routinely present at AAP local chapter meetings, visit community health centers, and other primary care settings to encourage referral to Part C/EI. (see earlier map).
- A standard EI referral form was developed and distributed statewide for use by medical practitioners.

- A toll-free line was established that, based on the caller's site location, rolls the call to the appropriate RAU for the catchment area. All referrals receive and acknowledgement of receipt.
- If the parent signs a consent, the medical practitioner who referred the child is provided information about the IFSP, progress reports, etc.

West Virginia Birth to Three (WV BTT) maintains Interagency Agreements with Title V, CHIP, and Medicaid for the early identification and referral of potentially eligible children.

Between July 2003 and June 2004, West Virginia Birth to Three developed processes and procedures to assure that infants and toddlers involved in substantiated abuse or neglect situations were referred to BTT for determination of eligibility for Part C/Early Intervention. Data below reflects an increase in the number of children referred to Part C from Child Protective Services over the past several years.

July 1, 2002 – June 30, 2003:	86 Children
July 1, 2003 – June 30, 2004:	187 Children

In total the percentage of infants and toddlers under the age of three receiving Part C services on December 1, 2004 was 3.2%. This represents an increase from 2.85% on December 1, 2003 and 2.6% on December 1, 2002.

### **Emergency Preparedness For Children With Special Needs**

Emergency and threat preparedness has highlighted the need for a more effective system to assure children with special needs are known to local officials, especially EMS personnel.

#### *Capacity to Address Needs:*

We have identified within the participants of CSHCN those who are ventilator dependent, have gastric tubes, and/or use wheelchairs for ambulation. The children/families are identified by county, city/town (address) and medical need; see the geographical mapping below:

We believe this is a starting place for an expanded identification of at-risk populations to occur which acknowledges that persons with special needs require special attention in the event of a state/national emergency. We are urging for similar scans to take place for the Deaf and Hard of Hearing, fragile elderly, etc.

We are also at the state planning table on Threat Preparedness calling for active involvement of persons who are deaf, hard of hearing, developmentally disabled, etc. in developing plans to assure the safety and security of persons who have special needs.



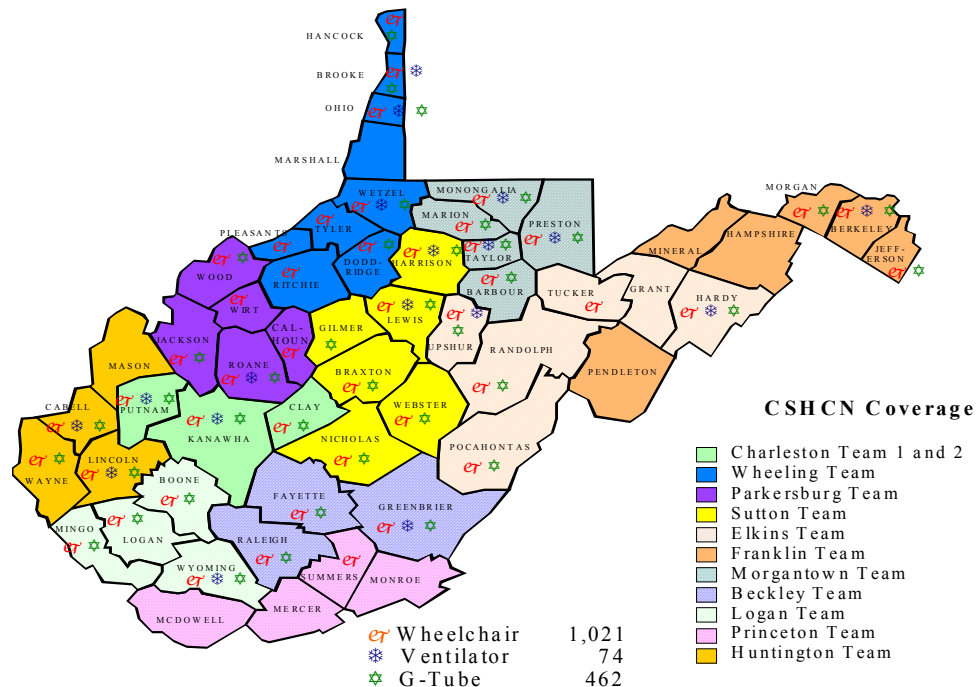
## ACCESS TO QUALITY HEALTH CARE

The question asked of consumers, providers, and other friends of Title V is, what is the most critical need you and/or your child have related to health? Families and providers alike responded, “access to comprehensive, affordable health care”.

In response to this, we’ve increased clinical capacity, offering clinic care at locations where demand can support, an increased payor mix, and have designed child and family assessment to account for both medical and psycho-social need.

Monitoring outcomes for children with special health care needs poses problems:

**Location of West Virginia’s Special Needs Children/Equipment and Team Coverage**



- Treatment of chronic conditions is only partially effective. Most of these children will never be cured, so the presence of a condition cannot be used as an outcome measure.
- Many external factors are important to successful outcomes but are not easily measured. The presence of the family and community supports is hard to measure yet everyone agrees they have positive implications for patient well-being.

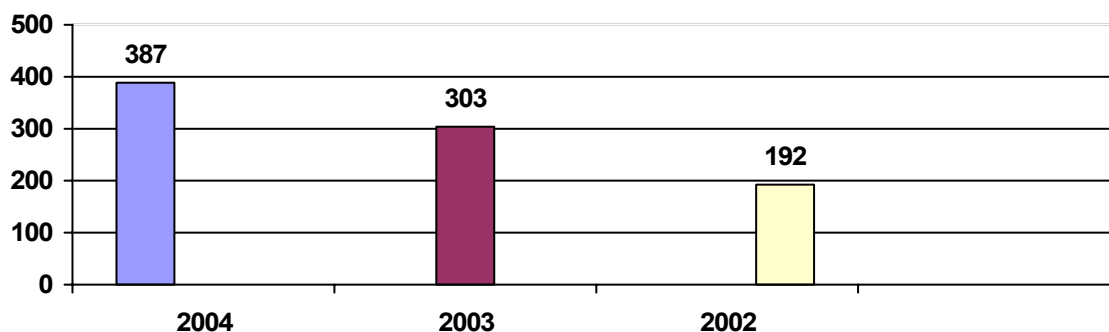
## **Nutrition Services**

To assure nutritional assessments and consultations MCFH established a grant with the Center for Excellence in Disabilities at West Virginia University. During CY 2004, a total of 370 children were assessed for nutritional concerns through thirteen nutrition clinics, telephone consults, or home visits. A nutritional screening tool was developed by the CED nutritionist to identify children at special risk for feeding or nutritional problems. Each CSHCN nurse is charged with using the screening tool with the enrolled children in his/her region for nutritional needs, and for holding at least one nutritional assessment clinic each year in conjunction with the CED nutritionist. These clinics allow children to be assessed locally without the need to travel long distances, and increases the efficiency of delivery of nutritional services offered by CSHCN.

When the Physician's Office Center at West Virginia University discontinued the nutritionist position in the Mountaineer Cystic Fibrosis Clinic in January 2004, the CED contracted nutritionist began attending that clinic to ensure service availability to these children. Under the auspices of the CED contract, the nutritionist now attends the FACES Clinic, a multi-disciplinary clinic for the treatment of pediatric craniofacial deformities at CAMC Women and Children's Hospital, Charleston, WV, to provide counseling to families of children with cleft lip and palate.

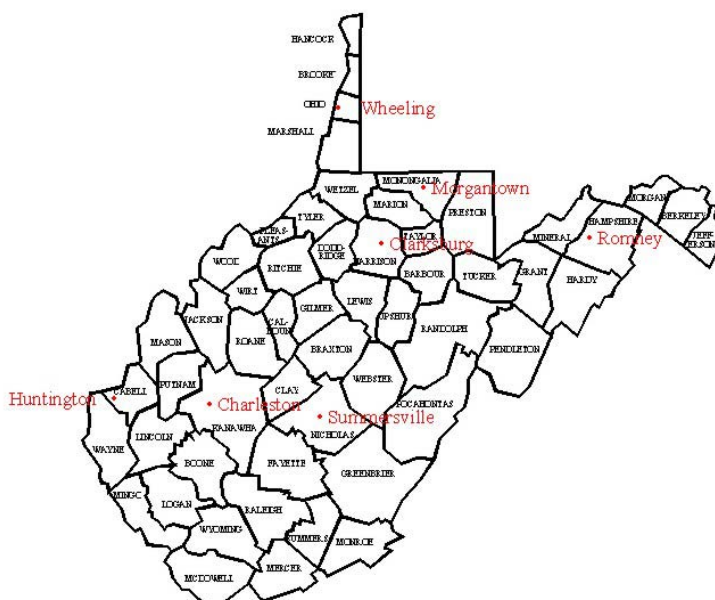
CSHCN collaborated with the Bureau of Public Health, Office of Nutrition's Special Supplemental Nutrition Program for Women, Infant, Children (WIC) to provide information at two WIC regional conferences entitled *Meeting Unique Needs* on July 27 and July 30, 2004. The CSHCN Social Service Director presented information about the CSHCN Program. The presentations by the two CED nutritionists were entitled *Serving Children with Feeding and Swallowing Problems* and *Nutrition for Children with Special Health Care Needs*. CSHCN nurses and social service workers attended the conferences along with WIC staff. Personnel from CSHCN and WIC were seated at the luncheon in their respective work region groups to provide a greater opportunity for networking and resource development.

## CSHCN Nutrition Services Number of Children Served



There are aggressive outreach efforts by UCED staff, including chart reviews of more than 400 active patients seen in pediatric cardiac and neurology services. Children who had identified needs were either seen by licensed Registered Dietitians at WVU Hospital or specialized teams in the employment of UCED at satellite clinics listed below. This outreach identified several children who were on anticonvulsants such as Depakote, a medication which has nutritional implications. Also, educational materials were developed and made available to practitioners caring for this population in an effort to increase nutrition referrals.

## Nutrition (Satellite) Clinics



## **Adequate Insurance**

**Children with special needs will have adequate private/public insurance to pay for services they need.**

While 80% of CSHCN program participants have Medicaid, the coverage is a result of aggressive action by Maternal, Child and Family Health.

### *Capacity to Address Needs:*

Given this charge, CSHCN has: (a) established eligibility determination processes that assure all health financing resources are explored. This includes eligibility determination for Medicaid (Title XIX) and CHIP (Title XXI). Children who are ineligible for either source of health care financing but have chronic, debilitating conditions covered by CSHCN have their care financed by Title V, if their income is at or below 185% FPL.

Children who do not meet any of the above eligibility requirements are offered care management through Systems Point of Entry (SPOE), in an effort to secure health financing. SPOE works with the Bureau for Medical Services to determine if the child is eligible for an optional Medicaid program called Children with Disabilities Community Service Program, which serves 120-130 severely disabled children per year who would not otherwise be eligible for Title XIX/Medicaid coverage. This program waives parental income to assure access to health care financing.

- All persons who are uninsured or underinsured are provided information on how to access Title XIX or Title XXI. Obviously, having health care financing is the best vehicle for assuring children receive on-going comprehensive care.
- Children who are diagnosed with chronic, debilitating conditions are obviously a priority for CSHCN, but we've also secured a similar commitment from the Social Security Administration Disability Determination Section to assure the populations identified by us receive priority handling.

Children who have CHIP, Medicaid, or Title V are eligible to be served by the Children with Special Health Care Needs Program, if they have a covered condition. This is an adaptation designed to support the needs of children and families since health care professionals are so very busy and can not cover office/clinic operational expenses when serving a disproportionate number of government sponsored patients. The end result is that children with special needs require more visits and more time per visit at a time when the clinical community cannot accommodate.

## **PARENT/FAMILY INVOLVEMENT**

Although West Virginia is a sparsely populated state, West Virginia families, like other families across the nation, find both the health care system and the community service system difficult to understand and navigate. This theme, while not new, is a constant among families.

### **Goals:**

- Increased family involvement
- Increasing awareness about available resources
- Identification of unmet need
- Improving coordination and collaboration

Families, young adults, representatives of health, mental health, social service agencies, education, etc. met regularly over 24 months. Discussions included the following topical areas:

- What kinds of services are available/unavailable to families and children?
- If a service is not available, why -- lack of money, program eligibility requirements, or no such service exists?
- How did they (families) find the existing services?
- What do family/agency representatives see as problems with the service system?
- How do families want to be involved?

### **Partners:**

- Families
- Mountain State Finance Parent Child and Adolescent Network (MSPCAN)
- Region II Family Network
- Mountain State Family Alliance
- West Virginia Department of Education
- Behavioral Health Providers
- Juvenile Justice
- Coalition for West Virginia's Children
- West Virginia Advocates
- Department of Health and Human Resources:
  - Mental Health
  - Child Welfare
  - Health – Maternal, Child and Family Health

### *Capacity to Address Needs:*

#### Results:

- Consensus that development of a full service array is the work of local, multi-county and regional groups. Several communities, with the help of universities, have completed a comprehensive assessment of all services available. A deeper study still on-going will assess affordability, quality and family satisfaction.
- System of Care Collaborative was an initial effort to improve family involvement in service development and increase community-based service capacity.
- All participants share the “system of care” philosophy, especially that families must be equal partners. The Collaborative did a study that identified West Virginia groups, organizations, and initiatives that encourage families to participate in decisions affecting their lives. Those agencies listed below offering stipends to families for participation are asterisked.

#### Service Planning Level:

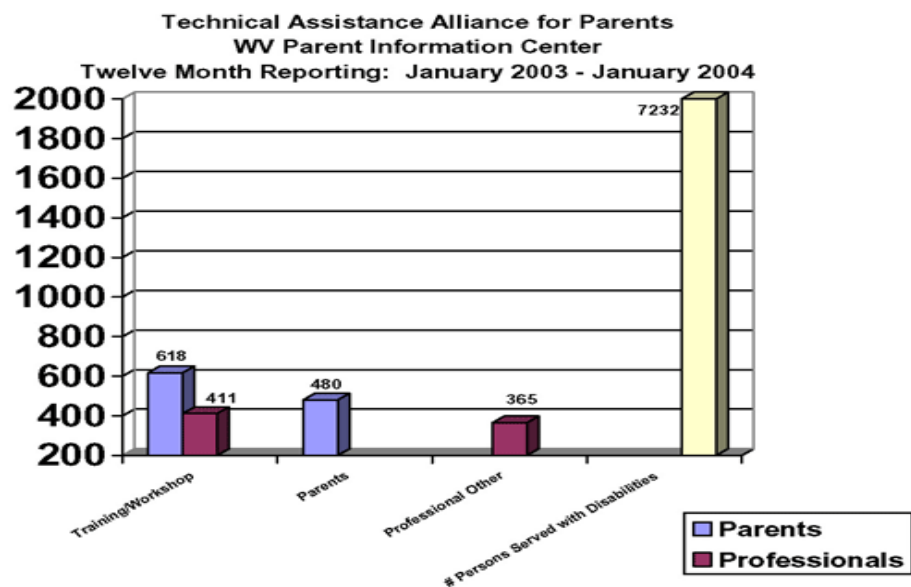
- Head Start
- Mountain State Parents, Child and Adolescent Network
- Region II System of Care – Mountain State Family Alliance
- Starting Point Centers
- WV Birth to Three\* (Part C/IDEA/MCFH Administered)
- Children with Special Health Care Needs\* (MCFH Administered)

#### Program Management Level:

- Family Leadership First\*
- Developmental Disabilities Council\*
- Family Resource Networks\*
- Head Start
- Mountain State Parents, Child and Adolescent Network
- Region II System of Care – Mountain State Family Alliance
- Governor’s Cabinet on Children and Families\*
- Starting Point Centers
- Step by Step
- Children with Special Health Care Needs\*
- WV Birth to Three\*
- Deaf and Hard of Hearing Commission\*

Policy Level:

- Family Leadership First\*
- Developmental Disabilities Council\*
- Family Resource Networks\*
- Deaf and Hard of Hearing Commission\*
- Head Start
- Children with Special Health Care Needs\*
- Mountain State Parents, Child and Adolescent Network
- Governor's Cabinet on Children and Families\*
- Step by Step
- WV Birth to Three\*



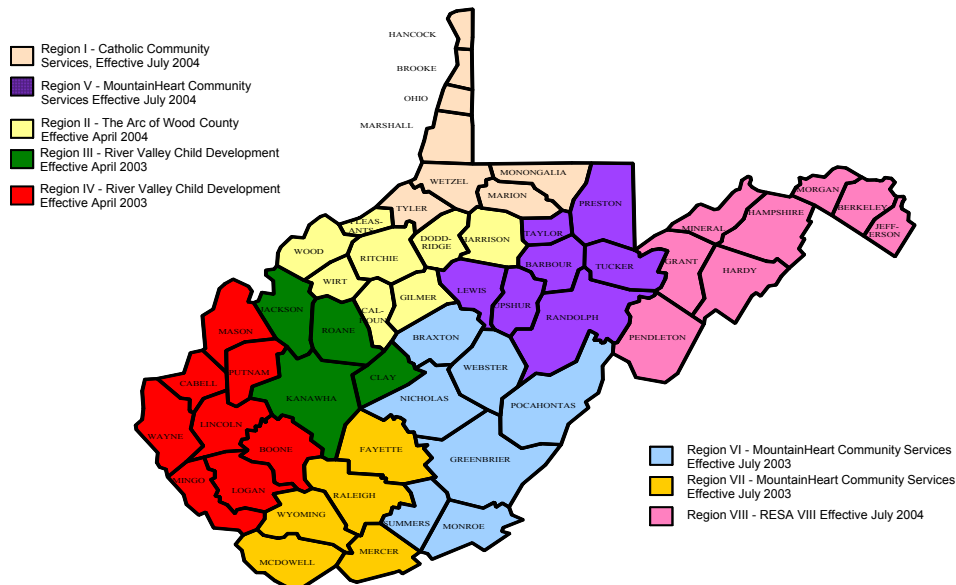
Parents participate in policy and procedures for Birth to Three (IDEA/Part C) and CSHCN.

- The Individuals with Disabilities Education Act (IDEA) has federal requirements for both state systems and services to individual children.
- States are required to have a statewide comprehensive, coordinated, multi-disciplinary interagency system for all eligible infants/toddlers and their families.
- Services for infants and toddlers must be provided in the child's home and/or in community settings in which children without disabilities participate.

West Virginia has made available Parent Partners in each region of the state (8), who are employed by Birth to Three (Part C) Regional Administrative Units funded by OMC FH. These Parent Partners serve as a liaison with families; and participate on the

Regional Administrative Unit Advisory Council, and agencies serving young children such as Headstart, WV Parent Training Institute, etc. Reports of their activities (presentations, advocacy and informing) are submitted quarterly to OMCFH.

## WV BIRTH TO THREE REGIONAL ADMINISTRATIVE UNITS



- West Virginia OMCFH also supports a network of parents who are employed by the UCED/UAP at West Virginia University. These Parent Network Specialists offer parent-to-parent support for families with children who have disabilities. The specialists attend CSHCN clinics, family support meetings, etc. A survey of families, by the Parent Network Specialists, identified the lack of understanding of IDEA, IEP process, civil rights related to classroom education, and service awareness as unmet needs.

<b>Parent Network Specialists July 2002 – December 2004</b>	
Number of Clients – CSHCN – 3 Years	863
Clinic Sessions Attended	203
Information and Referrals	4,420
IEP's Attended	59
Presentations	34
Total Product Dissemination	15,678
Care Notebooks Disseminated	577
Direct Client Contacts – CSHCN	1,979
Direct Client Activities	1,031
<b>Total Activities</b>	<b>5,902</b>



## **SPECIAL EDUCATION**

### **WV IDEA Self-Assessment Process**

Evidence-based decision making is essential to continuous improvement of educational services. Under West Virginia Achieves, our state meets the challenges of both the Individuals with Disabilities Education Act, Amendments of 1997 (IDEA 97) and the No Child Left Behind Act of 2001, which require states to measure progress toward important goals and performance indicators for all students. State and federal data reports, once used primarily for funding purposes, now are the basis for determining whether local education agencies (LEAs) and states have met their annual goals. The accurate and timely collection and analysis of student data are the foundation of effective school improvement and accountability.

The Self-Assessment Steering Committee included parents, individuals with disabilities, advocates, teachers, program administrators, institutions of higher education, private schools, vocational organizations, state agencies, state juvenile and correctional facilities, state operated programs and parent training agencies. Steering Committee members and additional members participated in subcommittees over a two-year period to analyze data and identify needs within eight areas identified by the U.S. Department of Education, Office of Special Education Programs. This analysis informed the Steering Committee's final recommendations, which were incorporated into the *West Virginia IDEA Self-Assessment Process, 2000-2002* report.

The Self-Assessment Process confirmed the significance of many current state priorities and revealed some new areas needing attention. Major areas of strength included:

- **Placement and services in natural environments/least restrictive environment** Students are receiving services in natural environments and with non-disabled peers.
- **Parent satisfaction**  
Parents report satisfaction with Part C services.
- **Compliance**  
Part B compliance monitoring, local CIMP (complaint, investigation, mediation, due process) are and dispute resolution processes well established systems.
- **Student outcomes**  
West Virginia's dropout rate is lower than the national average, and its graduation rate is higher.

Themes emerging across cluster areas and noted in both Part B and Part C analyses as areas of need included:

- **Training, recruitment and retention of personnel**  
Shortages of qualified personnel and a continuing need for professional development to improve the skills of current personnel were noted.
- **Interagency collaboration at the state and local levels**  
While significant interagency collaboration was noted, particularly for early childhood services and transition, more collaboration is needed for C to B transition, for services to students placed out-of-state by state agencies and for transition from school to post-school life.
- **Parent training and involvement**  
While many resources are provided for parent training and involvement, creative approaches are needed to reach more parents and to increase parent understanding and involvement in obtaining services for their children.
- **Student results**  
A continued focus on improving outcomes for students is essential. This includes better ways to measure outcomes, increasing the capacity of families of young children, improved developmental outcomes for children, higher academic achievement, fewer dropouts, more graduates and successful preparation for post secondary education or employment.
- **Data based decision-making**  
Almost every Subcommittee recognized a need for additional and/or more precise record keeping and data collection beyond the federally required data currently collected; collaboration between Part B and Part C and between Part B and post-school agencies and institutions to fill in data gaps; uniform ways to collect and analyze data for comparison between students with disabilities and their non-disabled peers; parent involvement data and analysis; and use of data in making decisions.

The West Virginia IDEA Self-Assessment Process report was submitted to OSEP in October 2002. West Virginia responded to requests for further information from OSEP in early January 2003. In anticipation of receiving a response to the report, the OSE and WV BTT scheduled a State Improvement Plan meeting January 28-30, 2003. At that time, Steering Committee convened to review the IDEA Self- Assessment report and make recommendations for priorities to be addressed in the state improvement plan. Recommendations of the Steering Committee were as follows:

- Conduct more in-depth analysis of issues related to high identification of students with disabilities and apparent disproportionality in specific disabilities to determine whether a problem exists, determine root causes and ensure that appropriate strategies are implemented. Specific issues included: whether eligibility criteria are implemented consistently or need revisions or

clarification; whether cultural differences contribute to over identification of African-American students.

- Training for regular education teachers, parents, principals and local Boards of Education.
- Recruitment and retention of highly qualified personnel for all positions providing direct services or administration of services to children and youth with disabilities.
- Disaggregate dropout rates and graduation rates by disability and analyze to determine why trends in these areas are unfavorable.
- Student results – focus on strategies for “instructional delivery”, including staffing patterns that pose barriers to appropriate services (e.g. students with various placements, disabilities and instructional needs being assigned to one teacher who is unable to meet the conflicting demands, although caseload limits are not out of compliance).
- Follow the major cross-cluster themes for plan development.

On March 3-4, 2003, the WV BTT – OSE Improvement Plan Committee met with Mid-South Regional Resource Center (MSRRC) staff to review the Steering Committee recommendations and to identify priorities within the cluster areas for the plan. The committee used a logic model to develop strategies for improvement for goals applicable to both Part B and Part C. Throughout March and April, the OSE and BTT groups met separately to draft the plans.

On March 28, 2003 the OSE draft was reviewed at joint meeting of RESA special education personnel and school improvement personnel and state staff. The West Virginia Advisory Council for the Education of Exceptional Children (Part B) and the Interagency Coordinating Council (Part C) reviewed and provided input for the respective plans.

#### *Capacity to Address Needs:*

Concurrently with the planning process implemented under IDEA, West Virginia has conducted major planning and development efforts under Title I and the No Child Left Behind Act of 2002. The OSE has developed the IDEA Improvement Plan to fit within the Department's plans for all students, that is, to meet applicable performance goals in the ESEA Consolidated State Plan and to meet adequate yearly progress requirements under the NCLB accountability plan.

Pursuant to its agreement with the U.S. Department of Education under Title I compliance, West Virginia has adopted new content standards and is redesigning its statewide assessment. The state has implemented new accountability and reporting policies, which include all students with disabilities grades 3-8 and 10, the grades assessed in West Virginia schools. The state's accountability plan for NCLB has been approved by the U.S. Department of Education. Under the accountability plan, all major

assessment and accountability policies and guidelines are being revised. The OSE has been directly involved in all these processes. Furthermore, under NCLB, the Consolidated State Plan includes required performance goals and indicators for all students.

More than 70 percent of West Virginia schools make the grade as part of West Virginia Achieves. State Superintendent of Schools David Stewart announced that 516 schools met Adequate Yearly Progress (AYP) during the 2003 - 2004 school year.

West Virginia Achieves is the state's No Child Left Behind accountability plan. In April, students in grades three through eight and 10 took the West Virginia Educational Standards Test (WESTEST). The WESTEST, which replaces the SAT-9, is an assessment that measures student achievement of the West Virginia Content Standards and Objectives (CSOs). The test provides information about student academic strengths and weaknesses by performance level descriptors. WESTEST identifies student levels of performance in the content areas of reading/language arts, mathematics, science and social studies. A student's performance is compared to academy standards rather than to the performance of a national sample of students. AYP is determined by the WESTEST and either attendance or graduation rate.

There were 156 schools identified as year-one AYP schools in 2003, that corrected their problem areas in 2004 and 37 Title I schools must provide school choice.

West Virginia Achieves test result highlights include:

- 516 schools met AYP (71 %)
- 82 additional schools met AYP in 2004 than in 2003
- 67% of all students met proficiency in math
- 77% of all students met proficiency in reading/language arts
- 100% of schools met AYP for attendance rate
- 99% of schools met AYP for participation rate
- 89% of schools met AYP for graduation rate

Results indicate that of the 204 schools that did not meet AYP in 2004, 136 schools did not meet AYP in the students with disabilities subgroup

"West Virginia Achieves is about closing the achievement gap," said Stewart. "We recognize that our schools still have some work to do before all students are proficient. Currently the West Virginia Department of Education is working with all fifty-five school systems in a support initiative Framework for High Performing School Systems. The Framework assists local boards of education in long term and systemic change designed to achieve the accountability results necessary by 2014."

The Framework for High Performing School Systems provides a leadership guide for transforming local school systems to "learning for all" organizations. This helps focus leadership and technical assistance activities of state, regional and local educational agencies; and provides a unified approach and common language for school system improvement in West Virginia.

West Virginia is one of the first states in the nation to receive full approval for its plan to reach the goals set forth by the No Child Left Behind Act. This accountability plan sets into place the methods by which the state will measure Adequate Yearly Progress (AYP), a cornerstone of NCLB. This monumental achievement was made possible with the guidance of the State Board of Education and the tireless work of WVDE staff members.

In 1990, the West Virginia Legislature through state code (WV Code §18-1-4) initiated education reform by providing six education goals for West Virginia, all of which are applicable to special education. The West Virginia Board of Education more recently has adopted seven refined goals, which relate to the legislative goals. In addition, several of the West Virginia Consolidated State Application for the Elementary and Secondary Education Act (referred to as No Child Left Behind or NCLB) goals are relevant to the IDEA State Improvement Plan.

### **Educational Efforts for the Deaf and Hard of Hearing Population**

Our friends and partners in the community who are deaf have told us that they overwhelmingly prefer to be referred to as deaf because it is simple and non-judgmental. It is believed that hearing people are squeamish about using the word deaf.

Comments from the Deaf Hearing Fair, Deaf Club(s), and members of the Deaf and Hard of Hearing Commission about hearing people and the deaf are as follows:

- I wish people would not say handicapped, disabled, or hearing impaired.
- Some people think deaf people are defective – we need help. In reality, I can do many things except hear!
- Deaf people dislike being labeled handicapped. I work and I pay taxes.
- To me, being deaf is a part of me.

People who are deaf have a far better understanding of the majority (hearing) culture that surrounds them than people who hear have of the deaf culture. Learning to communicate is critical.

1. Helping deaf children learn a language is the most important thing that parents and others can do:
  - a) Make available learning opportunities for parents who do not know how to sign.

- b) Encourage the development of supports from people who are deaf.
- c) Provide suggestions to help parents with communication skills, such as reminding parents to get the child's attention before talking, sign or talk face-to-face at eye level, and reduce background distractions are all helpful hints.
- d) Offer early learning opportunities in the deaf child's infancy using Ski\*Hi or Part C/Individuals with Disabilities Education Act/Birth to Three.

## 2. Organizing better education and training for teachers and interpreters.

- a) The West Virginia Deaf and Hard of Hearing Commission offers stipends and learning opportunities to increase the availability of RID certified interpreters. Skill building sessions were held April 23<sup>rd</sup>, May 6<sup>th</sup> and 7<sup>th</sup>, and June, 2005.
- b) Helping schools, teachers, and interpreters assists the education community in opening learning doors to children who are deaf.
- c) Community supports often need to be involved with families of children who are deaf, as the family wrestles with decisions about: (1) residential schools or (2) traditional school learning opportunity, with special supports for deaf children in hearing classrooms.

### *Capacity to Address Needs:*

West Virginia does have a residential school for the deaf and blind. The residential facility, West Virginia School for the Deaf and Blind, is state run and is experiencing a declining enrollment. The West Virginia School for the Deaf and Blind has a well-deserved reputation for academic excellence. In West Virginia, the school has significant support from the deaf community. Even so, the declining enrollment is attributed to P.L. 94-142, the controversial mainstreaming law. It is also understandable that many parents want their child who is deaf to be normal, to attend nearby schools and return home every afternoon.

To improve the service system and how we all work together, West Virginia state government provides: (1) MCFH monies yearly in the amount of \$20,000 to be used for interpreter education and certification; (2) the Department of Health and Human Resources, the umbrella agency for OMCFH, will pay for staff to learn sign language; (3) the Commission for the Deaf and Hard of Hearing is 100% financed by the State legislature; (4) the residential school is 100% financed by the State legislature; (5) the Developmental Disabilities Council is charged with offering diversity training and "People First" language education; (6) interpreter services are available to all state agencies under a special contract; (7) since 2000, all infants born in West Virginia are screened for hearing loss at birth and receive appropriate interventions; and (8) mass education to prevent hearing loss (i.e., teaching parents about detection of ear infection, encouraging breastfeeding since this practice strengthens the muscles that keep the tubes below the throat and the middle ear open, etc).

**Percentage of Total West Virginia Student Enrollment  
Who Are Deaf/Hard of Hearing  
Receiving Special Education and Related Service  
1994-2004**

	1994-95	1995-96	1996-97	1997-98	1998-99	1999-2000	2000-01	2001-02	2002-03	2003-04
Barbour	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.11%	0.08%	0.15%	0.16%
Berkeley	0.04%	0.04%	0.04%	0.02%	0.06%	0.06%	0.05%	0.09%	0.10%	0.11%
Boone	0.04%	0.04%	0.02%	0.04%	0.04%	0.09%	0.13%	0.13%	0.15%	0.11%
Braxton	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%
Brooke	0.02%	0.02%	0.00%	0.00%	0.00%	0.00%	0.00%	0.03%	0.03%	0.00%
Cabell	0.13%	0.11%	0.11%	0.13%	0.12%	0.10%	0.13%	0.13%	0.12%	0.12%
Calhoun	0.00%	0.00%	0.00%	0.19%	0.00%	0.00%	0.00%	0.00%	0.00%	0.08%
Clay	0.05%	0.05%	0.05%	0.05%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%
Doddridge	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%
Fayette	0.15%	0.12%	0.17%	0.18%	0.17%	0.16%	0.18%	0.14%	0.13%	0.16%
Gilmer	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%
Grant	0.00%	0.00%	0.00%	0.00%	0.05%	0.15%	0.15%	0.10%	0.05%	0.05%
Greenbrier	0.06%	0.05%	0.08%	0.10%	0.07%	0.10%	0.09%	0.07%	0.11%	0.07%
Hampshire	0.00%	0.00%	0.00%	0.00%	0.00%	0.06%	0.06%	0.06%	0.06%	0.03%
Hancock	0.06%	0.04%	0.02%	0.08%	0.06%	0.07%	0.11%	0.07%	0.09%	0.09%
Hardy	0.00%	0.00%	0.00%	0.00%	0.05%	0.05%	0.00%	0.04%	0.00%	0.00%
Harrison	0.07%	0.06%	0.09%	0.07%	0.07%	0.04%	0.05%	0.09%	0.09%	0.07%
Jackson	0.12%	0.06%	0.08%	0.08%	0.08%	0.08%	0.06%	0.06%	0.10%	0.10%
Jefferson	0.03%	0.06%	0.06%	0.06%	0.07%	0.04%	0.07%	0.04%	0.07%	0.04%
Kanawha	0.14%	0.15%	0.16%	0.17%	0.19%	0.17%	0.16%	0.16%	0.17%	0.17%
Lewis	0.03%	0.00%	0.07%	0.07%	0.00%	0.04%	0.07%	0.07%	0.04%	0.04%
Lincoln	0.21%	0.16%	0.14%	0.12%	0.12%	0.10%	0.13%	0.08%	0.15%	0.16%
Logan	0.00%	0.00%	0.00%	0.01%	0.03%	0.03%	0.06%	0.05%	0.15%	0.16%
Marion	0.23%	0.26%	0.26%	0.26%	0.25%	0.23%	0.19%	0.23%	0.22%	0.18%
Marshall	0.23%	0.25%	0.27%	0.22%	0.21%	0.16%	0.20%	0.13%	0.11%	0.11%
Mason	0.28%	0.28%	0.26%	0.18%	0.20%	0.19%	0.09%	0.12%	0.09%	0.07%
Mercer	0.10%	0.08%	0.08%	0.06%	0.06%	0.04%	0.05%	0.04%	0.05%	0.10%
Mineral	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%
Mingo	0.12%	0.14%	0.14%	0.17%	0.16%	0.18%	0.21%	0.20%	0.17%	0.23%
Monongalia	0.07%	0.11%	0.09%	0.17%	0.18%	0.16%	0.20%	0.17%	0.13%	0.12%
Monroe	0.05%	0.05%	0.05%	0.00%	0.05%	0.05%	0.10%	0.05%	0.09%	0.10%
Morgan	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.04%	0.04%	0.04%	0.04%
McDowell	0.12%	0.17%	0.13%	0.14%	0.09%	0.10%	0.15%	0.13%	0.16%	0.16%
Nicholas	0.20%	0.18%	0.20%	0.20%	0.25%	0.09%	0.07%	0.04%	0.09%	0.09%
Ohio	0.16%	0.14%	0.14%	0.14%	0.13%	0.17%	0.17%	0.17%	0.18%	0.15%
Pendleton	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%
Pleasants	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%
Pocahontas	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.07%	0.07%	0.07%	0.07%
Preston	0.17%	0.15%	0.11%	0.12%	0.12%	0.14%	0.14%	0.14%	0.12%	0.17%
Putnam	0.08%	0.13%	0.11%	0.14%	0.18%	0.17%	0.24%	0.21%	0.17%	0.16%
Raleigh	0.07%	0.09%	0.11%	0.13%	0.12%	0.11%	0.13%	0.18%	0.19%	0.19%
Randolph	0.44%	0.40%	0.40%	0.36%	0.41%	0.38%	0.29%	0.39%	0.44%	0.28%
Ritchie	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%
Roane	0.00%	0.00%	0.00%	0.00%	0.14%	0.14%	0.22%	0.19%	0.19%	0.12%
Summers	0.00%	0.00%	0.11%	0.00%	0.00%	0.00%	0.00%	0.06%	0.31%	0.43%
Taylor	0.04%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.08%	0.12%	0.04%
Tucker	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%
Tyler	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.13%
Upshur	0.12%	0.07%	0.05%	0.05%	0.05%	0.05%	0.08%	0.08%	0.08%	0.10%
Wayne	0.10%	0.10%	0.08%	0.09%	0.10%	0.09%	0.09%	0.13%	0.09%	0.09%
Webster	0.00%	0.00%	0.05%	0.11%	0.05%	0.06%	0.06%	0.06%	0.06%	0.06%
Wetzel	0.11%	0.13%	0.13%	0.18%	0.16%	0.17%	0.17%	0.14%	0.03%	0.09%
Wirt	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.10%
Wood	0.11%	0.12%	0.13%	0.10%	0.11%	0.13%	0.12%	0.14%	0.12%	0.15%
Wyoming	0.14%	0.13%	0.17%	0.12%	0.11%	0.17%	0.11%	0.14%	0.14%	0.12%
State	0.10%	0.10%	0.11%	0.11%	0.11%	0.11%	0.11%	0.12%	0.12%	0.12%

**Source: Exceptional Students in West Virginia's County School Districts – Fiscal Year 2004  
Office of Special Education, West Virginia Department of Education**

## **TRANSITION SERVICES INCLUDING SELF-ADVOCACY AND SKILL DEVELOPMENT**

Transition services for youth and young adults enrolled in CSHCN were continued as a high priority during CY 2004. During this period, 1,256 transition services were provided to youth, ages 14, 16, 18 and 20 years. Training of nurses and social workers about adolescent transition services was continued through the periodic nurse/social worker staff meetings. Written policy concerning delivery of adolescent transition services was expanded in the revised CSHCN Policy and Procedure Manual released to staff in April 2004. The transition screening tools were developed for use with adolescents ages 14, 16, and 17, and with young adults ages 18 and 20. These were also included in the manual with the expanded policy. This policy places a higher priority than previously on home and other face-to-face contacts for development of Patient/Family Care Plans for youth in transition.

Percentage of youth with special care needs who receive services necessary to make transition to all aspects of adult life.

- The U.S. Census 2000 cites 234,000 persons with disabilities, age 21-64, live in West Virginia. Only 32% are employed compared to 73.4% of persons without disabilities.
- Social Security Administration reports that approximately 3% of SSI recipients with disabilities in West Virginia work. This is one of the lowest percentages in the U.S.
- 2003 Social Security data for West Virginia indicated that over 72,000 workers with disabilities are receiving SSDI.
- 2003 Social Security data for West Virginia indicated that there are over 54,000 SSI recipients aged 18-64.
- If 1% of SSI and SSDI beneficiaries nationwide were to become employed, federal savings in disability benefits would total \$3.5 billion over the lifetime of the beneficiaries.
- A 2000 Harris Poll found that two of three people with disabilities preferred to be working.

Transition services are provided by CSHCN to all program participants.

- CSHCN nurses and social workers receive training in provision of adolescent transition services.
- Adolescent Transition Screening Tools were developed for use in care coordination with adolescents and young adults.
- CSHCN expanded services to the adolescent population, including transition services for youth 14 to 21 years.
- During CY 2004, 1,755 Patient Care Plans were completed to assure a continuum of comprehensive medical care and transition to adult care as appropriate.



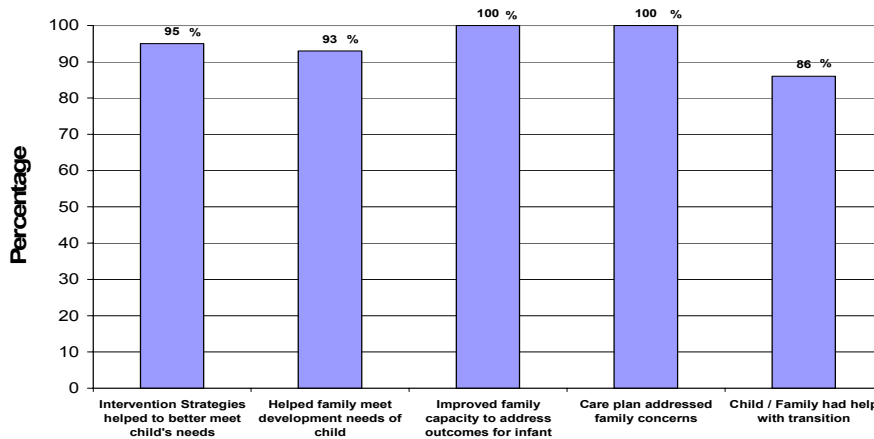
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In December 2004, CSHCN was awarded a Champions for Progress Incentive Grant for the purpose of expanding the program's transition services for youth and young adults. However, reorganization and staffing changes of CSHCN made continuation of the project unfeasible before implementation began on the project. Therefore, the request for funding was withdrawn.

Preparing students with disabilities for independent living skills is a goal of CSHCN. We do this in a variety of ways including partnership with the Division of Rehabilitation Services. The West Virginia Division of Rehabilitation Services offers school to work transition services for students with disabilities. Cooperative agreements between the Division of Rehabilitation Services, all fifty-five county school systems, the State Board of Education, and the School for the Deaf and Blind enabled 6,278 school students with disabilities to receive these services in FY 2002.

The West Virginia Birth to Three Transition Exit Survey was developed as a collaborative effort of WV Birth to Three, West Virginia Department of Education, Head Start, and Child Care. The survey is designed to address monitoring priorities of the U.S. Department of Education and provide information for improvement of family and child outcomes. Survey questions ask about the outcome of the child/family's transition; whether Part C services helped the family to meet their child's developmental needs; promoted the child's participation in daily routines; and helped to promote the child's development across developmental domains.

### Birth to Three Transition Survey Results (January through June 2004)



#### *Capacity to Address Needs:*

Support for transition services requires a financial and human resource commitment. The Division of Rehabilitation Services has, at present, 59 rehabilitation counselors to work with public schools, with 34 of 59 serving local education agencies full time. These counselors support students with transition from high school to appropriate vocational training, post-secondary education or employment.

With careful planning, the affected student “at the helm” and the involvement of families and school personnel, rehabilitation counselors developed 1,438 Individualized Family Service Plans for employment in FY 2002.

The Division of Rehabilitation Services works well with CSHCN to assure youth have ample opportunity for life transition plans. In addition, the West Virginia Division of Rehabilitation Services has a contract with the Social Security Administration, the Disability Determination Service Section (SSDI) responsible for handling Supplemental Security Income (SSI) disability applications filed by West Virginians. During Fiscal Year 2003, DDS processed 50,968 claims and had an overall accuracy rate of 92.7% for initial claims, which exceeds the Social Security Administration’s threshold for performance of 90.6%. DDS’s enhanced ability to provide citizens with disabilities more timely determination is of importance to West Virginia children with disabilities, especially those in MCFH programming (Part C/BTT and CSHCN) who receive expedited case handling based on a working relationship agreement between the two agencies.

As a result of the 1999 federal Ticket to Work legislation funded by the Social Security Administration, there is support for consumers receiving SSDI or SSI that want to work, called Benefits Planning, Assistance and Outreach Program (BPAO).

This unit serves as a resource for adult service transitioning for participants in CSHCN, especially since 80% of those served are Medicaid beneficiaries. Finding employment is not always easy for persons with a disability.

- The WORKFORCE West Virginia Career Centers and their partners provide a variety of employment-related services to the residents of West Virginia. Historically, opportunities for persons with disabilities had been few.
- Department of Labor funding has been provided to support community-based rehabilitation services for persons with disabilities and to enhance assistive technology capabilities.
- Community-based rehabilitative services provide vocational employment opportunities to address self-sufficiency.
- Persons needing special supports to transition to inclusive community living can be referred to Golden Rule, which pairs the individual with a golden retriever. The dogs are part of a training program offered by the Monongalia County Alternative Learning School. This creates an additional bonus in that school students learn and practice skills consistent with effective parenting.
- The Specialized Family Care Program (SFCP) is a statewide placement and family support system designed to serve the needs of children and adults with developmental disabilities who cannot live independently by:
  - Providing 24 hour, day-to-day care, support, training, and supervision to persons with developmental disabilities;
  - Including persons with developmental disabilities in family and community activities;
  - Participating in program planning to best address the needs of persons with developmental disabilities;
  - Receiving ongoing training, respite services, and financial support;
  - Agreeing to monthly monitoring and annual certification standards; and
  - Receiving personal satisfaction from having an individual grow to his/her maximum potential.

This program is an interagency collaboration between the West Virginia Department of Health and Human Resources and the Center for Excellence in Disabilities at West Virginia University, a part of Robert C. Byrd Health Sciences Center. The SFCP is funded under an agreement with the West Virginia Department of Health and Human Resources, Bureau for Children and Families.

The West Virginia Centers for Independent Living (WVCIL) is charged with assisting persons with disabilities to maintain independence. Their services for persons with disabilities include:

- Home modifications such as grab bars, widening doors, and building ramps;
- Medical equipment like wheelchairs, scooters, and shower chairs;
- Assistive technology to include eye glasses, phone amplifiers, communication devices ; and
- Vehicle modifications like hand controls.

The above services are provided under a grant agreement from the WV Division of Rehabilitation Services. In FY 2004, 233 persons participated in the program, while another 703 individuals are on waiting lists. This unmet need has been brought to the attention of the State Legislature, explaining that keeping people in their homes costs an average of \$1,702 per person, which represented an institutional savings of nearly \$16 million.

Since 74% of the persons served in FY 2004 were seniors, the Council is expanding its outreach efforts to youth by hosting the first West Virginia Youth Disability Caucus, July 29 – August 1, 2005. This four day leadership forum is open to youth with all types of disabilities, ages 16-21 years of age.

The participants or “delegates” at the Youth Caucus will have a unique opportunity to develop leadership skills, connect with mentors, learn about the disability rights movement, learn about the legislative process, make friends, and learn how they can make a difference in their communities.

Youth Caucus delegates will be preparing to become the new leaders in our state and the disability community. Activities include sessions with national speakers, small group activities, a dance, and a mock legislative session in the House Chamber at the State Capitol.

Financial support and identification of youth is occurring throughout the disability community including the CSHCN network.

Total public school enrollment continued to decline from 281,591 in 2002 to 280,561 in 2003, a decline of 1,030 or 0.36 percent. Statewide, 18% of the total West Virginia school enrollment was served in special education in 2003. This includes the West Virginia School for the Deaf and Blind and the Office of Institutional Education Program. This represents an increase of 329 students from 2002 or 0.7%. See reference to Deaf and Hard of Hearing.

**Percentage of West Virginia Students with Disabilities, Ages 6-21  
In the Least Restrictive Environment  
December 1, 2003**

	Percentage in Each Placement Within Area of Disability							
Area of Disability	A	B	C	D	E	F	G	H
Autism	33.53%	25.25%	39.45%	0.79%	0.00%	0.00%	0.20%	0.79%
Behavior Disorders	36.51%	34.85%	22.09%	0.04%	0.13%	0.36%	3.01%	3.01%
Speech/Language Impairments	98.77%	0.99%	0.17%	0.00%	0.00%	0.00%	0.00%	0.06%
Deaf/Blind	5.00%	5.00%	0.00%	10.00%	0.00%	80.00%	0.00%	0.00%
Deaf/Hard of Hearing	52.58%	25.06%	3.44%	1.23%	0.00%	17.20%	0.25%	0.25%
Specific Learning Disabilities	46.49%	48.89%	3.73%	0.01%	0.02%	0.05%	0.25%	0.56%
Moderate Mentally Impaired	0.95%	13.96%	82.82%	.48%	0.00%	0.00%	0.12%	1.67%
Mild Mentally Impaired	10.63%	63.01%	25.11%	0.00%	0.01%	0.01%	0.48%	0.75%
Profound Mentally Impaired	0.00%	0.99%	78.22%	2.97%	0.00%	0.00%	0.00%	17.82%
Severe Mentally Impaired	0.42%	3.81%	87.71%	1.27%	0.00%	0.00%	0.42%	6.36%
Other Health Impaired	41.85%	48.35%	8.33%	0.03%	0.06%	0.03%	0.17%	1.19%
Orthopedically Impaired	67.38%	20.32%	10.16%	0.53%	0.00%	0.00%	0.00%	1.60%
Traumatic Brain Injuries	57.63%	27.97%	8.47%	0.00%	0.00%	0.00%	0.00%	5.93%
Blind & Partially Sighted	55.61%	14.80%	2.24%	9.42%	0.00%	17.49%	0.00%	0.45%
<b>Total</b>	<b>50.85%</b>	<b>37.23%</b>	<b>10.38%</b>	<b>0.10%</b>	<b>0.02%</b>	<b>0.32%</b>	<b>0.35%</b>	<b>0.75%</b>

Continuum of Placements in the Least Restrictive Environment

- A = Regular Education: Full Time (0-20% Special Education)
- B = Regular Education: Part Time (21-60% Special Education)
- C = Special Education: Separate Class
- D = Special Education: Special School (Public)
- E = Special Education: Special School (Private)
- F = Public Residential Facility
- G = Private Residential Facility
- H = Homebound/Hospital Environment

**Source:** Exceptional Students in West Virginia's County School Districts  
Office of Special Education, West Virginia Department of Education  
Fiscal Year 2004

## **Self -Determination**

Self-Determination focuses on how people with disabilities live their own lives. Personal choice and control are the cornerstones of the self determination movement. Persons with disabilities control how public funds for services and supports are spent.

In West Virginia, almost everyone who has a disability and relies on public money to fund their services and supports are required to conform to sets of government and provide dictated rules and regulations. Services are controlled by these entities with the individuals having little choice in the types of supports they receive.

Increasingly, people with disabilities and their families are saying that the “one-size-fits-all” method of service provision is inadequate. The system should, instead, strive to meet each individual’s needs. Individuals want to set and pursue their own goals. They want to live in the place and type of housing they choose, obtain competitive employment and take responsibility for the money they spend while making a contribution back to their communities. They want to live their own lives and make their own choices, just as people without disabilities do every day.

### *Capacity to Address Needs:*

The WV Self-Determination Initiative is comprised of a group of individuals and organizations dedicated to instilling the philosophy of self-determination for people with disabilities into the mainstream of life in West Virginia.

The long term objective of the Initiative is to help assure freedom and real choice for all individuals with disabilities, and give them the authority over the resources they need, both monetary and otherwise, to live full and productive lives in the communities of their choice. The Initiative strives to create a unified voice in the disability community to eliminate institutional bias and bad practice, and replace it with a consumer directed care system.

The Initiative will work to help increase the sense of personal power for people with disabilities by giving individuals direct, personalized control over the services they receive and the budget used to purchase those services. By shifting the power from agencies and providers to the individual, people with disabilities will finally be afforded the same civil rights that those without disabilities enjoy.

One-day training sessions are being offered by the WV Developmental Disabilities Council and the Center for Self-Determination throughout the State. The sessions are scheduled for June, 2005 and teens are strongly encouraged to participate, as a part of the adolescent to adulthood transition effort.



DD Council – Center for Self-Determination Training Locations, as of 6/05

### **Mountaineer Camp**

The OMCFH also encourages youth with disabilities to participate in the Mountaineer Camp designed to help children and teens develop self esteem, social skills and self reliance while they participate in recreational and social activities.

Mountaineer Camp was established in 1985 and is operated by Mountaineer Spina Bifida Camp, Inc., a private, non-profit organization. Mountaineer Camp activities are geared toward camper participation. Camp nurses and physicians are present to help campers with their medical needs and camp counselors assist with daily living activities and participation activities. Camp counselors are recruited from WV colleges and high schools, and receive training to prepare them for Mountaineer Camp.

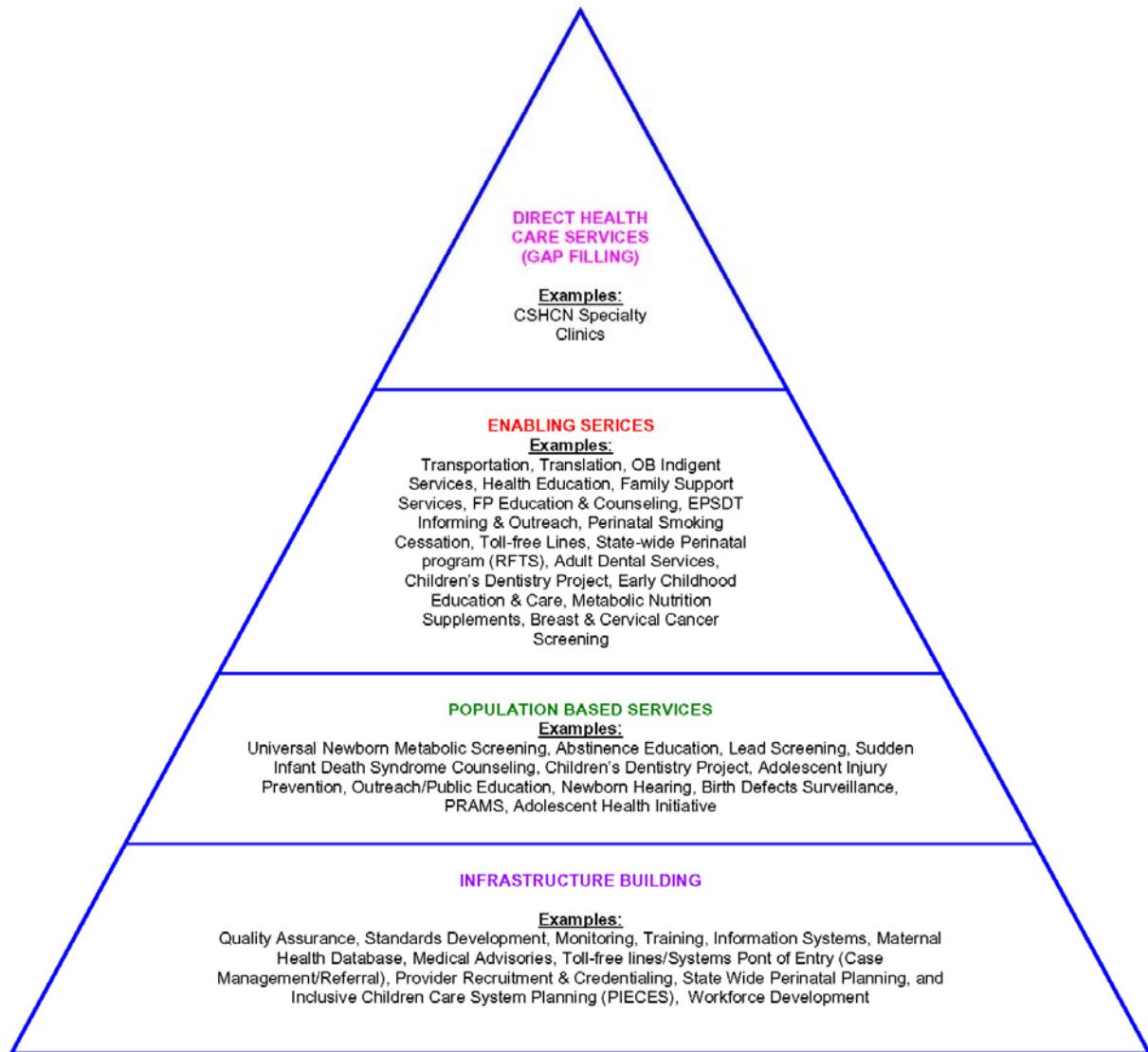
All funding for Mountaineer Camp comes from donations, grants, and fund-raising. Campers' families are required to pay a small percentage of the cost of their child's week of camp, to help cover the expenses of meals and lodging.

Mountaineer Camp is one of only a few camps in the U.S.A. designed specifically to meet the needs of youth who have spina bifida or myelodysplasia. The Office of Maternal, Child and Family Health is pleased to be a camp sponsor and supports the camp by providing nurses from the Children with Special Health Care Needs Program.

## **D. CAPACITY**



## West Virginia-Office of Maternal, Child and Family Health Services Core Functions Schema



**Capacity Assessment Across MCH Essential Services  
West Virginia – Maternal, Child and Family Health**

<b>DIRECT SERVICES</b>	
<b>Goals</b>	<b>Findings</b> Strengths are in <b>Red</b> Weaknesses/Needs are in <b>Blue</b>
<p>Children with Special Health Care Needs is administered by Maternal, Child and Family Health on behalf of multiple payors, including Title XXI, Title XIX, Title V, and insurance.</p> <p>Definition: Children, birth to age 21, with certain chronic, debilitating medical conditions. Service includes medical care management, social service, and community supports, including adult transition planning.</p>	
1. Adequate Funding	<ul style="list-style-type: none"> <li>• MCFH works diligently to secure a source of health care financing for every child. This has resulted in 80% or more of the children becoming Medicaid or CHIP beneficiaries.</li> <li>• Medicaid and public health share in the administrative cost of the program.</li> <li>• Not every chronic disease is a Children with Special Health Care Needs covered condition because of insufficient funding for Title V.</li> <li>• Medical practitioners provide services at a rate less than routine and customary.</li> </ul>
2. Assuring the capacity and competency of the public and personal workforce.	<ul style="list-style-type: none"> <li>• The in-house workforce are all licensed social workers and nurses.</li> <li>• The West Virginia University Health System has been a strong resource to the program for 30+ years, providing medical expertise, as well as medical guidance on policy.</li> <li>• Medical providers are board certified</li> <li>• Staff are all trained on People First Language, and leadership participates on the Developmental Disabilities Council, Family Voices, Deaf and Hard of Hearing Commission, Social Security Administration-Title V Workgroup, etc.</li> <li>• Parents and consumers participate on the CSHCN Advisory.</li> <li>• Parents, hired through a Title V agreement with the UAP/University Center for Excellence in Disabilities participate in program policy development, brochure and public informing material development, etc.</li> <li>• Staff and practitioners are trained in confidentiality law and practice.</li> </ul>

DIRECT SERVICES	
Goals	Findings Strengths are in Red Weaknesses/Needs are in Blue
	<ul style="list-style-type: none"> <li>•</li> </ul>
3. Assessment of maternal and child health status using data.	<ul style="list-style-type: none"> <li>• Integrated data systems support program reporting.</li> <li>• Claims are handled by one vendor, and each payor pays their part based on the enrolled beneficiary.</li> <li>• Information from data and population-based surveillance systems are used to link children to specialized care.</li> <li>• Staff have access to on-line databases for literature searches.</li> <li>• Staff have access to Medicaid/CHIP eligibility files.</li> </ul>
4. Link women, children and youth to health and other family services and assure access to comprehensive quality systems of care.	<ul style="list-style-type: none"> <li>• Specialty/multidisciplinary clinics are held throughout the state.</li> <li>• Medical practitioners and state staff travel to sites in the community to offer medical care that would otherwise be unavailable.</li> <li>• Toll-free responders and social workers respond to health and human service queries.</li> <li>• Individual, client-directed care plans are completed on all participants.</li> </ul>

**Capacity Assessment Across MCH Essential Services  
West Virginia – Maternal, Child and Family Health**

<b>ENABLING SERVICES</b>	
<b>Goals</b>	<b>Findings</b> Strengths are in <b>Red</b> Weaknesses/Needs are in <b>Blue</b>
<p><b>RFTS Project:</b></p> <p>Arranges care for government sponsored obstetrical populations and children up to age 1 (Title V, Title XIX, Title XXI) that meet pre-established medical criteria. State staff have responsibility for care protocol development and dissemination, provider recruitment, and system development that assures patient access to quality, comprehensive, timely care. RFTS services are provided through a community-based network of nurses, social workers, and physicians.</p> <p>1. Adequate Funding</p>	<p><b>Insufficient Funding</b></p> <ul style="list-style-type: none"> <li>RFTS (perinatal services), especially those related to case management and behavior risk reduction, such as smoking cessation and parenting education, have been negatively affected by health care cost inflation; see Attachment (Cue: RFTS service reimbursement chart).</li> <li>MCFH has tried unsuccessfully to persuade insurers to purchase case management and other enabling services for their pregnant and newborn beneficiaries. However, nurse liaisons from insurers participate in RFTS skill-building and program meetings.</li> </ul>
<p>2. Assuring the capacity and competency of the workforce.</p>	<ul style="list-style-type: none"> <li>All medical practitioners serving RFTS enrollees must have formal working agreements with OMCFH establishing the expectation that patient care will be provided in accordance with ACOG standards; that MCFH's Quality Assurance team will be given access to patient files for chart reviews, etc.</li> <li>MCFH maintains a masterlisting of providers to facilitate patient choice of medical practitioners.</li> <li>All nurses and social workers serving as RFTS practitioners are required to: (a) show proof of licensure and (b) must routinely</li> </ul>

ENABLING SERVICES	
Goals	Findings Strengths are in Red Weaknesses/Needs are in Blue
	<p>participate in training/skill-building.</p> <ul style="list-style-type: none"> <li>• Trainings offered by MCFH are evaluated by participants so process changes to better meet participant need is addressed.</li> <li>• Every year approximately 1/3 of the RFTS practitioner workforce is monitored, and 100% receive a plan of correction if indicated.</li> <li>• Perinatal and Women's Health maintains a medical advisory to assure expert medical guidance is provided the Office. Membership is statewide and multiple disciplines participate.</li> <li>• Program facilitates the working relationship agreement between family practice physicians to assure the availability of obstetrical and/or surgical back-up in the event of patient care need. The formalization of these arrangements is to improve patient care and ease transfer of care.</li> <li>• State program leadership participates in tertiary hospital(s) grand rounds to educate new practitioners about available community resources.</li> </ul>
3. Assessment Using Data	<ul style="list-style-type: none"> <li>• Patient data systems are linked with vital statistics.</li> <li>• MCFH/Title V funds the assessment at birth of <u>all</u> West Virginia newborns. This includes identification of infants at risk of post-neonatal death, developmental delay, and/or newborn hearing. All this information is used by MCFH/RFTS/Newborn Hearing to assure support and intervention occurs for "at risk" infants.</li> <li>• Technology capacity and personnel to maintain and upgrade computer infrastructure is in place.</li> <li>• Adequate computer hardware, support and training are available for the local administration of the RFTS program (8 Regional Lead Agencies statewide).</li> </ul>
4. Link women, children, and youth to health and other services to assure access to comprehensive, quality systems of care.	<ul style="list-style-type: none"> <li>• Women who receive pregnancy tests at any of the 153 sites offering this free service are provided pregnancy counseling options. Those women electing to carry the pregnancy who are without insurance are given a</li> </ul>

ENABLING SERVICES	
Goals	Findings Strengths are in Red Weaknesses/Needs are in Blue
	<p>shortened Medicaid eligibility form and a confirmation of pregnancy that is mailed to local DHHR offices to apply for health coverage.</p> <ul style="list-style-type: none"> <li>• Systems Point of Entry and toll-free responders all have access to a statewide community resource guide that is on-line and portrays health and human services, which improves referral efforts.</li> <li>• As referenced earlier, standards of care are established by OMCFH/RFTS and application of these standards is applied to government sponsored patients (Title V/Title XIX). See earlier comments on this subject.</li> <li>• Participates in local and state chapter meetings of ACOG.</li> <li>• All direct service practitioners, called Designated Care Coordinators, are charged with securing health care financing for newborns. Other units in MCFH are charged with assuring provider availability.</li> </ul>

## Capacity Assessment Across MCH Essential Services West Virginia – Maternal, Child and Family Health

POPULATION-BASED SERVICES	
Goals	Findings Strengths are in Red Weaknesses/Needs are in Blue
<p><b>Newborn Metabolic Screening:</b> All infants born in WV are screened for Phenylketonuria (PKU), Hypothyroidism, Galactosemia, Sickle Cell Disease (mandated) and certain other hemoglobinopathies upon voluntary request by diagnostic tests and treatment arrangements, if indicated. Also provides PKU special foodstuffs. Children who are positive are referred to Children with Special Health Care Needs for support services.</p> <p><b>Newborn Hearing</b> All children born in WV are screened at birth for hearing loss. Children who fail the screen are followed and assisted in obtaining further diagnostic care to assure that children with a loss receive appropriate medical intervention.</p> <p><b>Birth Score</b> Population-based surveillance activity administered by WVU in partnership with OMCFH to identify infants at risk of post-neonatal death in the first year of life and to provide appropriate interventions for those determined at risk.</p>	
1. Adequate funding in all critical areas.	<ul style="list-style-type: none"> <li>Insufficient funding for metabolic screening.</li> <li>Passage of Fee-for-Service rule enabling the state to charge for this function.</li> </ul>
2. Assuring the capacity and competency of the public and personal health workforce.	<ul style="list-style-type: none"> <li>Public Health surveillance systems are in place that allow MCFH to monitor, diagnose and secure intervention/treatment.</li> <li>These population-based services are evaluated using data.</li> <li>State Lab serves as a sole source for metabolic screening and follow-up occurs as a Title V service by nurses.</li> <li>Trained community-based workforce is in place to assure additional assessment and intervention occurs.</li> <li>Practitioners, audiologists, ENTs receive additional training paid for by Title V to enhance services to newborns.</li> <li>Title V monies have been used to purchase diagnostic hearing equipment for use at strategic locations where access to service was non-existent.</li> <li>All licensed birthing facilities are trained to complete and report the birth score and other screening processes.</li> <li>Population-based public health screening activities under the leadership of MCFH have</li> </ul>

POPULATION-BASED SERVICES	
Goals	Findings Strengths are in Red Weaknesses/Needs are in Blue
	been codified.
3. Assessment of maternal and child health status using data.	<ul style="list-style-type: none"> <li>All newborns, including those birthed at home, are screened for risk (birth score), hearing and metabolic. These processes are tracked using data.</li> <li>Data collection is timely.</li> <li>Data from vital records transfers to MCFH and is used to engage families in the health care system, especially those related to birth defects.</li> </ul>
4. Link maternal and child health populations to services and assure access to comprehensive, quality systems of care.	<ul style="list-style-type: none"> <li>Children who are identified with metabolic disorders, hearing loss, birth defects and/or developmental delay are all linked to appropriate community and medical resources.</li> <li>There are 240-280 practitioners available to provide care for children who are identified as "at risk" using the birth score, or assure children receive diagnostic and treatment follow-up when the child failed a hearing screen.</li> <li>There are 600+ practitioners to offer services to infants/toddlers who are developmentally delayed. Enrolled practitioners are required to have state-provided curriculum training in addition to a license in a discipline such as OT, PT or speech.</li> <li>Families electing to participate in RFTS, which serves at risk kids, or Birth to Three (infants diagnosed with developmental delay) <u>select</u> service practitioners.</li> <li>OMCFH actively recruits practitioners to offer direct care, with attention to medically underserved areas.</li> </ul>



**Capacity Assessment Across MCH Essential Services  
West Virginia – Maternal, Child and Family Health**

<b>INFRASTRUCTURE BUILDING</b>	
<b>Goals</b>	<b>Findings</b> Strengths are in <b>Red</b> Weaknesses/Needs are in <b>Blue</b>
1. Adequate funding in all critical MCFH areas/programs	<p><b>Insufficient funding in all areas, especially:</b></p> <ul style="list-style-type: none"> <li>• Family Planning (Title X, XIX, V, State Appropriation)</li> <li>• Perinatal Program, RFTS (Title V/State Appropriation)</li> </ul> <p>Authority to accept and award grants, establish priorities, rate setting and policy development.</p> <p>Efficient use of all fiscal resources to support MCH programs; i.e., CHIP, Medicaid, insurances are all payors.</p>
2. Assuring the capacity and competency of the public and personal health workforce...  (See references in Needs Assessment	<p>WV public and private agencies that finance and/or provide health and social services to MCH populations:</p> <ul style="list-style-type: none"> <li>• CHIP</li> <li>• Medicaid</li> <li>• Child Care Agencies</li> <li>• Information/Referral Agencies</li> <li>• University Health Systems</li> <li>• Community Health Centers</li> <li>• Hospitals</li> <li>• Private Practice Physicians</li> <li>• Local Health Departments</li> <li>• UAP (UCED)</li> </ul>
	<p>Organizational relationships are strong and formalized:</p> <ul style="list-style-type: none"> <li>• AAP State Chapter</li> <li>• ACOG State Chapter</li> <li>• NASW</li> <li>• WV Primary Care Association</li> <li>• WV PEIA</li> <li>• Coalition for WV Children</li> <li>• WV Family Alliance</li> </ul>

INFRASTRUCTURE BUILDING	
Goals	Findings Strengths are in Red Weaknesses/Needs are in Blue
	<ul style="list-style-type: none"> <li>• Developmental Disabilities Council</li> <li>• Commission for the Deaf and Hard of Hearing</li> <li>• WV Chapter MOD</li> <li>• WV Hospital Association</li> <li>• WV Insurance Commission</li> <li>• WV Dental Association</li> <li>• Association of Local Health Departments</li> <li>• WV Family Voices</li> </ul>
	<p>Medical-Consumer Advisories are in place for all MCFH programs, CSHCN, Perinatal and Women's Health, Pediatrics, BCCSP, etc.</p> <p>All direct providers of services for MCFH populations (Family Planning, EPSDT, CSHCN, Part C IDEA/Birth to Three, BCCSP, etc.) receive on-site quality assurance monitoring that includes chart review for compliance with national/state level performance expectations.</p>
3. Assessment of Maternal and Child Status using Data	<p>Integrated data systems, including direct link to vital statistics (birth/death records, etc.).</p> <p>Technology capacity and personnel to maintain and upgrade computer infrastructure.</p> <p>Capability of on-line data at local service area (RFTS, BCCSP).</p> <p>Data collection system that is able to feed timely data to programs; for example, birth defect information used by CSHCN for outreach.</p> <p>Access to on-line databases for literature searches.</p> <p>Adequate computer hardware and support personnel.</p>
4. Link women, children, and youth to health and other family services and assure	Teaming is routinely offered for staff to develop understanding of legislative process.

INFRASTRUCTURE BUILDING	
Goals	Findings Strengths are in Red Weaknesses/Needs are in Blue
access to comprehensive, quality systems of care.	<p>Families/consumers are provided financial support to participate in the Fairshake Network to learn the legislative process and advocacy skills.</p> <p>MCFH toll-free lines and Systems Point of Entry personnel maintain information about programs and services statewide related to health and human services.</p> <p>OMCFH out-stationed staff participate in community driven activities such as the Family Resource Network to provide awareness about public health/MCFH (Title V).</p>

## **E. CHALLENGES**

## **E. CHALLENGES:**

Following are additional concerns facing West Virginia:

- **FINANCIAL MANAGEMENT**
- **THE WV PUBLIC HEALTH WORKFORCE SHORTAGE**
- **INSURANCE ISSUES**

### **FINANCIAL MANAGEMENT**

West Virginia is haunted by its fiscal past. Today's impressive efforts to get financial management in line are weighted under by more than \$9 billion in accrued liabilities from the state's pension and workers' compensation funds. Compare that to a general fund budget of about \$3 billion, 55 percent of which goes to education, and you can grasp the magnitude of the problem. True, "the hole isn't getting any deeper," says Budget Director Roger Smith. But it's sure deep enough to make progress on other fronts an uphill battle.

In fact, more than 11 percent of the state's revenues are now spent annually on the \$6 billion-plus pension liability. At the end of last fiscal year, some financial advisers wanted to bond out a large portion of this debt. But the state's auditor and treasurer successfully fought the move in court, on the grounds that West Virginia's constitution requires any debt to be approved by voters. There also was a debate over whether this was good financial policy to begin with. "If you can borrow your way out of debt, we'd all do it," says the auditor, Glen B. Gainer III.

How did West Virginia get into this mess? As former tax secretary Robin Capehart explains, the state for years was conservative about giving its employees raises and instead rewarded them essentially with pension commitments—IOWs they could collect in their retirement years. Now, as the population ages, the bill is coming due. Businesses were never required to fund workers' comp properly, and asking them to do it now would bankrupt some of them. The state is trying to partner with companies to make workers' comp solvent on a gradual basis. But it won't be easy, and it threatens to undermine the state's efforts at economic development. "It's hard to be profitable when all of a corporation's profits are going into workers' comp," says state Comptroller Andrew Fizer.

With all this taking place, it's easy to ignore the positive efforts being made in West Virginia. The state has one of the best revenue estimating operations in the country. Controls in over spending have been very successful; in fact, the budget ran a \$54 million unappropriated surplus last year and projects a \$191 million surplus for fiscal year 2005. The state plans to use much of that money to pay off a small portion of the accrued liabilities. Financial reporting is exemplary. The state has maintained a rainy-day fund, and even made some significant progress in its cash management.

The one thrust at solid financial control that may have gone a bit too far is the set of procedures aimed at protecting the state from future contracting scandals. There are so many layers of contract oversight— especially in the Attorney General’s Office—that it can take forever to get anything done.

At the bottom of most of the state’s difficulties is money—not will or intelligence. West Virginia’s financial condition creates problems all across the spectrum of government. Agencies complain that they don’t have the personnel data they need to do adequate workforce planning. And though the tax department has finally been given some money to upgrade its technological capacity, it “has been underfunded for a long time,” says Fizer. “And that’s stupid, because it’s the state’s lifeblood.”

Sometimes it just seems the deck is stacked against West Virginia. It’s one of only four states, for example, that have complete responsibility for all roads other than city streets, and as a result, about 37,000 miles of road are on the books. For the vast majority, transportation officials can’t place a dollar amount on their maintenance needs—except that they know there’s a lot of work out there. “There isn’t enough money,” says one transportation official. “We’re still trying to fund the Appalachian Highway System, which was approved in 1966.”

## **THE WV PUBLIC HEALTH WORKFORCE SHORTAGE**

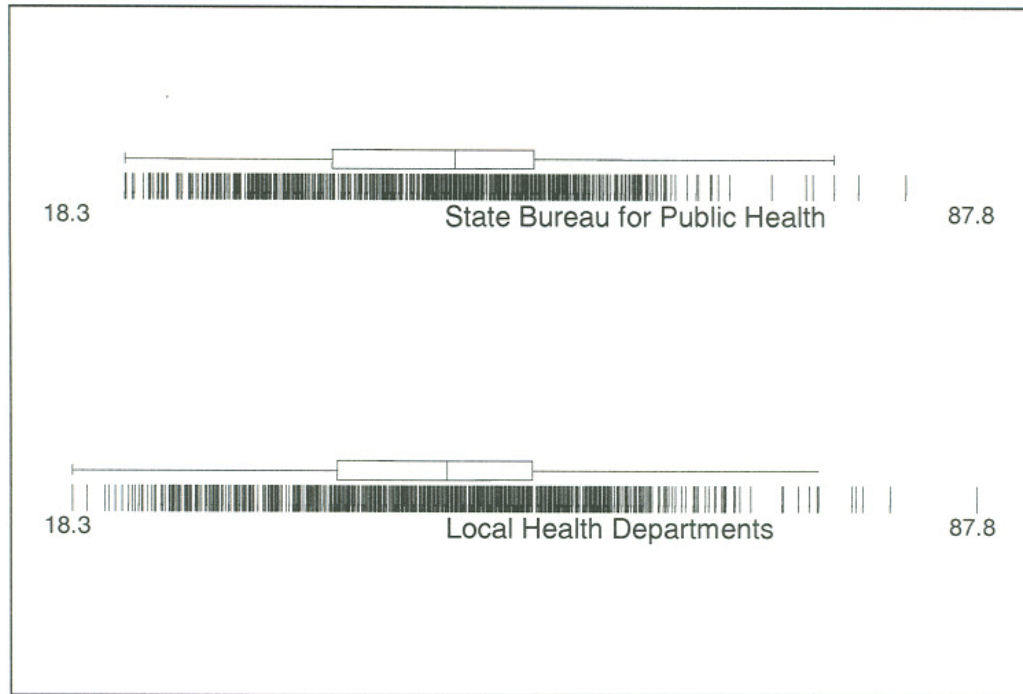
In West Virginia, the Bureau for Public Health, WVDHHR, is the State Health Agency, housing the State Health Officer. The 55 counties have independent Local Health Departments, and county Boards of Health, which are organized into 48 different agencies. There is no State Board of Health, or equivalent.

However, all of these governmental public health agencies share a common personnel system, through the State Division of Personnel. An extract of the Division of Personnel records showed 1,681 persons employed by all governmental public health agencies during the first week of January 2003. Of these 958 were employed in Local Health Departments (LHD), and 722 were employed in the Bureau for Public Health (BPH). A significant number of contractual employees are employed in both settings.

### **Ages of State and Local employees**

The average age for BPH employees was 46.4 years, and 46.1 years for LHD employees. One-dimensional scattergrams provide a graphic representation of the age distribution of the West Virginia Public Health Workforce. The median age (represented by the vertical line in the middle of the box diagram) was 47.8 years for BPH employees and 47.0 for LHD employees.

**Figure 1 - Age Distribution, WV Governmental Public Health, January 2003**



### Functional Classification of WV Governmental Public Health Workforce

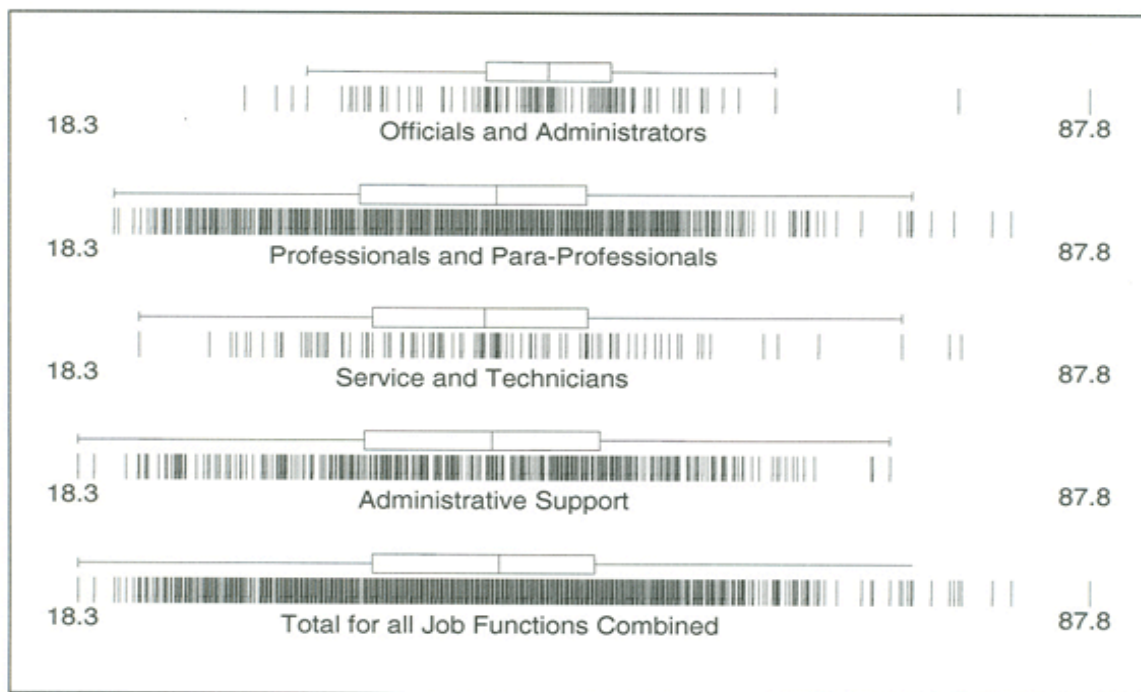
West Virginia has split authority between the State Health Agency (Bureau for Public Health) and the 48 Local Health Agencies serving all 55 counties. However, we may be the only state where these two sets of employees are governed by the same personnel rules and regulations - those of the WV Division of Personnel. The following 4 categories provide a reasonable way to classify every governmental public health worker in WV, and can be matched to other workforce development activities in the state.

<b>Job Function</b>	<b>Count</b>	<b>Average Age</b>	<b>Median Age</b>
Officials or Admin	123	50.5	50.6
Professionals	996	45.8	47.0
Service	109	46.4	46.2
Admin Support	453	45.8	46.7

Job Function	Count	Mean	Std. Err.	[95% Conf. Interval]	
Officials	123	50.54959	.7583006	49.04846	52.05073
Professionals	995	45.83709	.3396585	45.17056	46.50362
Service	109	46.40642	1.036735	44.35143	48.46141
Admin Support	453	45.83929	.5128284	44.83147	46.84712

The following scattergrams and box-and-whiskers diagrams illustrate the data above. Not surprisingly, we have an aging workforce. It should be noted that West Virginia had the highest median age population in the country in the 2000 census.

Figure 2 - Age Distribution, WV Governmental Public Health, by broad Job Function, January 2003





What is surprising, however, is the looming crisis in our leadership positions. Recent efforts of the Public Health Transitions Project, Turning Point, and the Threat Preparedness Initiatives have allowed for an influx of Professionals, Para-Professionals, and Administrative Support personnel. However, the tight cluster of Senior Managers (Officials and Administrators) in the upper quartile of their age distribution represents an especially vexing policy dilemma. Replacing these individuals will take time and skill. They also embody an "institutional memory" that is totally undocumented. Another dilemma is shown by the wide variation in the ages of our professionals. The diagram well illustrates the large number of professionals working into their retirement years.

Addressing these emerging issues is the fundamental purpose of the Public Health Education Program within the Higher Education Policy Commission. Such an enormous problem can only be solved through close collaboration between:

- The Workforce Development Unit of the Bureau for Public Health,
- The Association of Local Health Departments,
- The Workforce Investment Division of the WV Economic Development Office, the US Department of Labor Registered Apprenticeship Program,
- The WV Community College System,
- The WV Department of Education,
- WV Community Voices,
- WV Community-Campus Partnerships for Health, and
- The Higher Education Policy Commission (HEPC), which coordinates and implements consistent policies at all publicly funded colleges and universities in the state.<sup>1</sup>

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<sup>1</sup>W. Va. Code \* 18B-IB-4 grants HEPC broad powers and duties relating to the provision of public higher education. W. Va. Code \* 18B-IB-4(b)(4) specifically makes HEPC responsible for academic program review and approval at the state institutions of higher education and gives specific authority "to implement needed changes" in those academic programs. W. Va. Code \* 18B-2A-3 provides that the Chancellor shall supervise the governing boards of the state higher education institutions and is responsible "for the coordination of policies and purposes of the governing boards." Authority to coordinate the state medical schools and provide assistance to the governing boards on matters relating to medical education and health sciences is given to the Vice-Chancellor for Health Sciences, who serves under the Chancellor, in W. Va. Code \* 18B-IB-5. W. Va. Code \* 18B-16-1 et seq. further provides for the coordination and provision of health sciences education, rural health care initiatives, and primary health care education sites. Even though the position of the Vice-Chancellor was eliminated for budgetary reasons in the 2003 Regular Session of the W. Va. legislature, the authorities of the Office remain, and can reasonably be presumed to reside with the Chancellor, who can delegate them to his Public Health Education Program.

Separating the state and local employees by Job Function demonstrates that the same trends described above are facing local governments as much as state policymakers.

<b>Average Ages</b>	<b>State</b>	<b>Local</b>
Officials or Admin	50.3	<b>50.9</b>
Professional	46.6	<b>45.3</b>
Service	44.4	<b>47.9</b>
<b>Admin Support</b>	<b>44.8</b>	<b>46.6</b>
<b>Median Ages</b>	<b>State</b>	<b>Local</b>
Officials or Admin	50.6	<b>50.7</b>
Professional	48.2	<b>46.0</b>
Service	44.4	<b>47.2</b>
<b>Admin Support</b>	<b>45.8</b>	<b>48.0</b>

This data shows that service and administrative support workers at the LHD's are older than their state counterparts, while the professionals at the BPH are older than corresponding professionals at the local level. From a policy perspective, this means that we will soon face a loss of the folks who "get things done" at the local level, and professional expertise at the state level. Never has it been more essential to develop core curricula, continuing education, and distance-learning capability to protect the health of the public. Never has it been more critical that all the institutions of higher education demonstrate coordination and cooperate "to prepare a workforce of healthcare professionals to address the medical consequences of bioterrorism and other public health emergency preparedness and response issues."<sup>2</sup>

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<sup>2</sup>Excerpt from Federal Register Vol. 68, No. 86, Monday, May 6, 2003 HRSA-03-099 (BTC DP) 93.996

## **System Response to Anticipated Personnel Shortages (on-going)**

### **Office of Nutritional Services - "Growing Team WIC"**

"Growing Team WIC" project was undertaken in 2005 to meet two main goals: 1) build the skills, competency, and credentials of current and potential nutritionists who reside in the state; and, 2) develop a competency-based program designed to identify, hire, train, mentor, and manage nutrition professionals and para-professionals to provide quality nutrition services.

Outcomes anticipated include enumerating the workforce and forecasting needs to the year 2010; defining a career ladder with appropriate and practical job categories; identifying skill sets needed and used for each job category; identify appropriate and accessible training methods; inform staff about scholarships and financial assistance available for advancing education and training opportunities; and report and disseminate findings to interested partners such as USDA, National WIC Association, and ASTPHND. Several staff working on this project (Denise Ferris, Susanne Gregory) are also involved in workforce development issues with ASTPHND.

### **Office of Laboratory Services - "WV Laboratory Workforce Development - A Public/Private Partnership Addressing Current and Future Laboratory Workforce Shortages"**

The purpose of this project is to examine the current and future public health and clinical laboratory workforce trends in West Virginia and stimulate future interest in clinical laboratory careers. Nationally, there is a shortage of qualified clinical laboratory professionals (also known as medical technologists or clinical laboratory scientists). According to federal laboratory statistics, the average age of public health and clinical laboratory workforce is approximately 48. The workforce situation is projected to worsen with an aging population of the current clinical laboratory workforce. In 10 years, many of the "laboratorians" are eligible for retirement and not enough students are currently in the system to fulfill the future vacancies. Shortages of clinical laboratory professionals will also directly impact public health laboratory staffing who have to maintain the same level of professional education and competency as the private sector.

Objectives of this project include: 1) Evaluating the current West Virginia laboratory workforce and projecting the need for laboratory professionals to include clinical laboratory scientists or medical technologists, in a ten year timeframe. The WV Laboratory Workforce Questionnaire, a data gathering tool, is now in progress. 2) Developing a "Clinical Laboratory Career Ladder" based on federal and state regulatory clinical laboratory personnel requirements, broad competencies and degree of knowledge required for each rung of the "career ladder". Data from laboratory regulatory agencies and laboratory personnel licensure is used for a basis in developing the Clinical Laboratory Scientist Career Ladder. 3) Stimulating awareness of laboratory

professions with particular emphasis on the WV Public Health Laboratory. Activities include involvement with awareness of clinical laboratory careers at the middle and high school level; school visits and distribution of laboratory career literature and posters 4) promoting lab careers to science teachers and counselors primarily at the middle school level across WV; and volunteers available at career fairs.

### **Office of Community Health Systems, Division of Local Health - "Public Health Nursing CEU to Certification Project"**

The West Virginia Bureau for Public Health: Public Health Nursing CEU to Specialist Project is a pilot project designed to support competency-based training for public health nursing. It will allow the 274 nurses employed by local health departments in West Virginia to become experts in the field of public health nursing and recognized specialists in public health nursing. The project is a collaborative effort among the WV Department of Health and Human Resources, Bureau for Public Health, WV Association of Local Health Administrators, and the WV Higher Education Policy Commission, Healthy Careers Partnership Leadership Team. Initial funding has been provided by the Southeast Public Health Training Center.

In West Virginia the "Average WV Public Health Nurse" is 48.5 years old, female, has an associate degree or diploma training, never uses a computer, needs continuing education credits (CEUs), prefers satellite or training close to work, has worked more than 15 years as a full-time nurse, and makes between \$25,000 and \$40,000 annually.

Local health departments are the foundation of the "critical health infrastructure" that must be able to detect, respond, and mitigate a wide range of potential threats, including flooding, epidemics and other man-made and natural disasters. However, they are only as good as the staff within them. Dedicated nurses are maintaining our quality of life on a shoestring budget. Building off these concepts, this project seeks to document the actual work tasks being done by nurses in local health departments, utilize the Nursing Liaison Committee to pilot and evaluate a competency-based curriculum, including modules related to bioterrorism and general threat preparedness, and to develop the program for delivery through the WEB-CT platform. These modules will be marketed, delivered, and tracked through WV-TRAIN, the recently deployed Public Health Learning Management System for West Virginia (<http://wv.train.org>).

Public health nurses have a rich history of being actively involved in disaster planning and response. Today, public health nurses need to continue to contribute on emergency response teams. They need additional education in agents of mass destruction, incident command system, enhanced skills in epidemiological surveillance and investigation of infectious disease, knowledge of methods to distribute and administer medications and vaccines in mass clinic settings, expertise in communication of health risks to community members, and to work with new partners. The WV Public Health Nursing Workforce is loyal, talented, and has always "been there" and "does

what it takes"; but, this same workforce is older, expecting to retire soon and needs more competently trained public health nurses to succeed them.

There are three broad goals and objectives for the "Public Health Nursing CEU to Specialist Project:.

1. In Phase 1, train 15 regional-based nurses to become experts in the field of public health nursing and recognized as specialists in public health nursing in West Virginia. Activities will include designing courses on the WVNETIWebCT server and linking to WV-TRAIN, the WVBPH learning management system and conducting a WorkKeys assessment to profile the actual work tasks being done by nurses in local health departments.
2. In Phase 2, support competency-based training to enhance the public health skills of all nurses in the WV Bureau for Public Health. Activities will include a "roll out" of courses to all nurses in local health departments, then a "roll out" to all nurses in the WV Bureau for Public Health.
3. In Phase 3, seek opportunities for networking, partnership and sustainability for public health nursing competency-based training. Activities will include seeking curriculum approval with academic centers for continuing education credits, with potential for these credits to qualify as course work toward a BSN or other type of academic credentialing; "rollout" to all nurses as CEUs only; seeking funding opportunities to support long-term operating costs, stipends or scholarships.

We will evaluate success throughout all phases of this project, tracking the number of nurses enrolled and/or reaching specialty status, year to year. Every nurse enrolling in the project, beginning in the pilot phase, will be required to "pass" a competency-based post course test, in order to be eligible for the specialty honor. We will also conduct a face-to-face meeting with the fifteen "pilot" nurses to evaluate the mode of learning. The expected outcome of the Project would potentially qualify candidates for a "West Virginia Public Health Nursing Specialist" certification. In addition, the curriculum will be approved for continuing education credits, with potential for these credits to qualify as course work towards a BSN or other type of degree or credentialing.

## **INSURANCE ISSUES**

A recent article in the Charleston, WV Gazette in 2005 noted that:

West Virginians with health insurance through private or government employment could pay among the nation's highest additional premium charges this year to cover the unpaid health bills of the uninsured.

Using various government statistics and surveys, the health-care consumer group Families USA determined the average American with employer-based insurance will pay an extra \$920 for a family policy in 2005 and \$340 for an individual policy.

In West Virginia, family policies will include \$1,800 in extra costs - the second highest amount in the nation. That's 15 percent of the average \$11,890 a family policy will cost. Individual policies will have the third highest add-on in the country: \$660 or 15 percent of the predicted yearly cost of \$4,372.

The report, the first to put a dollar value on the burden the insured bear for caring for the uninsured, correctly portrays the importance of providing for the nation's 48 million people without insurance, said Kathleen Stoll, the report's author. Families USA is based in Washington and Stoll lives in West Virginia's Eastern Panhandle.

"It's definitely an awareness and educational tool to let insured people know that when we talk about the uninsured, it's not just somebody else's problem," she said.

The number of people without insurance and the cost of health care and insurance rise in tandem, she explained. As medical costs and insurance premiums go up, fewer people can afford services and insurance, which results in higher outstanding bills and more uninsured. Premiums increase in turn.

According to the report, the predicted costs of caring for the uninsured now will rise substantially in the next five years. By 2010, 53 billion people could be without insurance and the health-care costs not covered by the uninsured themselves will increase from the current \$43 billion to \$60 billion.

Nearly 30,000 more West Virginians will be without insurance by 2010 for a state total of 282,000 uninsured - or 15 percent of what the population will be, the report predicts.

The report's estimates and predictions are "conservative," Stoll said. The report assumes the uninsured pay one-third of their medical bills and the rest is paid by government programs and - primarily - by people with health insurance. In calculating the cost of health care to the uninsured, however, researchers used the rates insurance companies would pay, not what hospitals charge.

"From a hospital, you may face a bill of \$100,000, but we would only count a bill of \$30,000," Stoll said. The report also assumes that government programs like Medicaid do not change in the next five years, although the program faces a \$10 billion reduction over the next four years, The Associated Press reported in April, 2005.

So, could the current and future costs of treating people without health insurance be higher: "They sure could," Stoll said. "Many of my colleagues would agree that they are higher."

The situation could also improve by 2010 if action is taken, she said.

In West Virginia, Gov. Joe Manchin's administration is on the eve of implementing programs intended to provide insurance to those who don't have it, said the governor's spokeswoman, Lara Ramsburg, who had not read the report as of Wednesday.

At the end of this month, the governor will begin promoting the West Virginia Small Business Plan, which will help small businesses provide insurance to their employees, she said.

The majority of people without health insurance either have a job or live in a family in which at least one person works, according to the Families USA report. Many businesses, particularly small ones, can't afford to offer health benefits and many low-wage workers couldn't pay for a plan if one were offered.

In addition to the small business plan, the Access WV program, which helps high-risk individuals get insurance, will begin next month, she said. In addition to those programs, Manchin has also focused on preventive care, Ramsburg said.

More government programs will not solve the uninsured problem, said Jim Binder, a pediatrician at Marshall University and co-president of the state chapter of Physicians for a National Health Program; trimming the bureaucracy will. The money and staff that go into approving and disqualifying people for health care would be better used on medical treatment, he said. "The bureaucracy is incredibly expensive and we could cover everybody if we had one system" like that in other industrial nations, he said.

Although Binder has not read the report, he credited it for trying to initiate sincere dialogue about the nation's health-care system. "As [people] start to realize the economic costs they're going to say, 'We can't keep doing this.'"

## **F. SUMMARY**



## **F. SUMMARY**

Although West Virginia has financial woes and many health care issues such as smoking among pregnant women, infants born prematurely, infants born with low birth weight, obesity and asthma, the WV OMC FH has woven together a patchwork of funding streams to create a system of care for women, infants, and children, including adolescents and those with special health care needs. The WV OMC FH has developed strong partnerships across the State with the medical community, private sector, as well as community health centers and local health departments, all in an effort to assure access. Medicaid has purchased services for their beneficiaries at the request of Title V but they, too, are facing financial woes.

The State MCH program is in jeopardy of not being able to carry out the mandate to assure family health. Inflation has seriously reduced the purchasing power of Title V funds and compounded with stagnant funding levels over the past five years leaves West Virginia and states across the Nation unable to meet public demand.

It is clear that we cannot support all current programs and services at the existing level. In response to budget shortfalls, the WV OMC FH has advocated for the purchase of those services most critical to the health of maternal and child populations--family planning, prenatal care, support of EPSDT, population based surveillance programs, CSHCN services, etc. Another strategy that the WV OMC FH has undertaken is reduction of cost wherever possible. The family planning formulary has been changed to accommodate the purchase of generic treatment medications and contraceptives. These pharmaceuticals are purchased in mass and stored at a government operated warehouse that is supported by multiple programs, including West Virginia Healthy Start/HAPI. West Virginia is also efficient with resources, often administering programs and services that are used by multiple payor sources such as Title XIX and XXI. To assure that federal resources are maximized, all uninsured children and pregnant women seeking services must apply for Title XIX. As stated earlier, if the patient is ineligible for Title XXI or Title XIX, Title V resources are used to pay for their care.

Another threat to the WV infrastructure is workforce shortages precipitated by aging as discussed in the Challenges section.

The West Virginia five year needs assessment indicates the following priorities in the MCH population groups:

- A. Pregnant women, Women of childbearing age, Mothers and Infants
  - 1. Decrease smoking among pregnant women
  - 2. Reduce the incidence of prematurity and low birth weight
  - 3. Reduce the infant mortality rate

B. Children and Adolescents

1. Decrease the incidence of fatal accidents caused by drinking and driving
2. Increase the percentage of adolescents who wear seat belts
3. Reduce accidental deaths among youth 24 years of age or younger
4. Assure that children and families access health care financing and utilize services

C. Children with Special Health Care Needs

1. Maintain and/or increase the number of specialty providers in health shortage areas through recruitment and credentialing
2. Assure that children and families access health care financing and utilize service
3. Increase Newborn Metabolic Screening tests to include the 29 nationally recommended tests

## **G. ATTACHMENT**

## **MEDICAL CONDITIONS ELIGIBLE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS PROGRAM BY ALPHABET**

- Absence of limb: complete, partial, congenital, or acquired
- Accessory of scaphoid
- Achondroplasia
- Adrenomyeloneuropathy
- Agammaglobulinemia (Bruton's disease)
- Agenesis corpus callosum
- Angiokeratoma corporis diffusum
- Anomalies of skull
- Anophthalmus
- Anterior horn disease
- Anteversion of femur
- Aphakia\*
- Arachnodactyly
- Arteriovenous Malformation of the brain
- Arthrogryposis
- Aseptic necrosis
- Atresia ear(s)
- Absence of bladder, kidney, ureter, urethra
- Accessory of bladder, kidney, ureter
- Addison's Disease
- Congenital adrenal hyperplasia (CAH)
- Aldehyde deficiency
- Alport's Syndrome
- Ambiguous genitalia
- Annular pancreas \*
- Anomalies of face and neck
- Anomalous pulmonary venous return
- Anorchism
- Aortic atresia, stenosis,
- Apert's Disease (acrocephalosyndactylia)
- Atonic bladder
- Atrial defects: AV canal, endocardial, cushion, ostium primum, ostium secundum, septal (ASD)
- Baker's cyst
- Barrett's metaplasia
- Benign neoplasms of skin
- Biliary atresia
- Blackfan-Diamond
- Bladder neck obstruction
- Blepharophimosis\*
- Bone cysts (limited to surgery)
- Bone tumors (benign and malignant), Ewing's Sarcoma
- Brachial plexus
- Brain tumor (limited to residuals following surgery)
- Bronchiectasis\*
- Bronchopulmonary dysplasia
- Burns (limited to late effects and grafts)
- Camptodactyly
- Cataract
- Caval varus
- Cerebral palsy
- Cerebral palsy (hemiplegia, paraplegia, quadriplegia, Little's Disease)
- Cerebral degeneration
- Cervical rib
- Chalazion\*
- Charcot-Marie-Tooth Disease
- Cholesteatoma
- Chromosome 17 deficiency
- Chronic serous otitis media\*\*
- Chronic granulomatous disease \*\*
- Cleidocranial dysostosis
- Cloaca
- Club foot or hand

- CNS complications of hypoxia/anoxia
- Congenital dislocations/bands
- Congenital anomalies of larynx, trachea, bronchus\*
- Congenital nerve deafness
- Congenital auditory anomalies/atresia
- Contractures
- Corneal ulcer\*
- Cornelia De Lange's Syndrome
- Coxa valgus/varus
- Cranial nerve disorders/palsy
- Crohn's disease
- Cubitus valgus/varus
- Carnitine deficiency
- Chronic UTI with reflux\*\*
- Chronic nephritis\*,\*\*
- Chronic hydronephrosis/hydronephritis\*\*
- Chronic glomerulonephritis (Bright's Disease)\*\*
- Cirrhosis of liver
- Citrullinemia (ornithine deficiency)
- Cleft lip/palate
- Clinodactyly
- Coarctation of aorta
- Congenital central hypoventilation syndrome
- Congenital heart block (complete or partial)
- Cortical necrosis\*
- Craniosynostosis
- Crouzon's disease
- Cushing's Disease
- Cystic Fibrosis
- Decubitus ulcers (pressure or cast ulcers)
- Defects of bladder valves
- Deformities ear/nose
- Double outlet of right ventricle
- Dandy-Walker Syndrome
- Demyelinating disease CNS
- Detached retina
- Diaphragmatic hernia
- Dislocated lens\*
- Dislocations, congenital/chronic, especially hip
- Duane's Syndrome\*
- Dystonia
- Ehlers-Danlos Syndrome
- Encephalocele
- Encephalopathy, specified
- Engleman's Disease
- Epidermoid cyst
- Epiphysiodesis
- Epithelial corneal dystrophy
- Erb's palsy
- Esophageal atresia/stricture
- Esotropia, exotropia, heterotropia, hypertropia, hypotropia\*
- Exostosis (dyschondroplasia \*\*)
- Ebstein's anomaly
- Emphysema (congenital)
- End stage renal disease/chronic renal failure
- Endocardial fibroelastosis
- Epidermolysis bullosa
- Excessive skin/tags
- Exstrophy of bladder
- Fabry's disease
- Fanconi's Syndrome
- Fistula, anal/rectovaginal
- Fanconi's disease
- Fistula (anal, recto-vaginal, tracheoesophageal)
- Fractures-one year post trauma (malunion and nonunion)
- Friedreich's ataxia
- Gardner's Syndrome
- Gastroschisis

- Gastroesophageal reflux, Nissan required
- Genu valgus/varus
- Glaucoma (acquired or congenital)
- Guillian Barre's Syndrome (limited to residuals)
- Glottic webbing
- Goldenhar's syndrome
- Gorlin-Goltz syndrome
- Hallux valgus/varus
- Hammer toe
- Hand-Schüller-Christian Disease
- Hemangioma (port-wine stain)
- Hemivertebra
- Hemolytic Uremic Syndrome
- Herniated disc
- Hirschsprung's disease (megacolon)
- Hurler syndrome
- Hydrocele
- Hydrocephalus (congenital, acquired, obstructive, communicating)
- Hydroureter
- Hypercalcemia/hyperkalemia\*\*
- Hypogammaglobulinemia
- Hypogonadism
- Hypophosphorous rickets
- Hypoplastic left heart syndrome
- Hypospadias
- Hypo-/hyper-tonia
- Ichthyosis
- Imperforate anus
- Internal tibial torsion
- Juvenile rheumatoid arthritis (JRA)
- Kartagener's Syndrome
- Kawasaki's disease
- Keratoglobus
- Keratosis
- Klippel-Feil Syndrome
- Klippel-Trenaunay-Weber Syndrome
- Krabbe's (leukodystrophy)
- Kyphosis
- Labyrinth dysfunction
- Laceration of nerve, tendon, muscle (limited to residuals of trauma)
- Lacrimal cyst/duct obstruction/dacryostenosisLagophthalmus
- Laryngeal stenosis/paralysis
- Laurence-Moon-Biedl Syndrome
- Legg-Perthes Disease
- Lordosis Syndrome
- Lowe Syndrome Lymphangioma
- Lymphedema (Milroy Syndrome)
- Macrotia
- Marfan's Syndrome
- Marie-Strümpell Disease
- Mastoiditis
- McCune-Albright Syndrome (Albright-McCune)
- Meatal stenosis
- Medullary cystic disease\*
- Meningitis residuals
- Meningocele
- Menke's Disease
- Metatarsus adductus/varus
- Methylmalonic acid deficiency
- Microcephaly
- Micropsia
- Monosomy 7
- Moya-Moya Syndrome
- Multiple sclerosis
- Muscular dystrophy (Beckers. Duchenne)
- Myelomeningocele
- Myositis ossificans
- Myotonic brain disorders
- Nasal/vocal polyps/obstruction\*
- Necrotizing enterocolitis
- Nemaline myopathy

- Neurodystrophy
- Neurofibromatosis (von Recklinghausen's)
- Neurogenic bladder
- Neuropathy
- Nevus (strawberry, pilosis, basal cell)
- Noonan's
- Nystagmus\*
- Obstructive neuropathy\*
- Obstructive uropathy (at or below the bladder)
- Omphalocele
- Osler-Weber-Rendu Syndrome/disease
- Ossicular defects
- Osteochondrosis (Blount's Disease)
- Osteogenesis imperfecta
- Osteomyelitis
- Otosclerosis
- Papilledema associated with hydrocephalus
- Paralysis/paresis (congenital, acquired)
- Perforations/adhesions of drum head
- Petrositis
- Pinealocytoma
- Poliomyelitis (limited to residuals)
- Prader-Willi's Syndrome
- Progressive bulbar palsy
- Prune belly Syndrome
- Ptosis
- Pyloric stenosis
- Panhypopituitarism
- Patent ductus arteriosus (PDA)
- Pectus carinatum
- Pectus excavatum
- Pierre-Robin Syndrome
- Polycystic kidney
- Polyposis
- Pseudo hermaphroditism
- Pulmonary atresia, stenosis
- Q-T Syndrome
- Renal Agenesis\*
- Renal hypertension due to vascular disorder\*
- Retinoblastoma (limited to residuals)
- Retinopathy of prematurity
- Rett syndrome
- Rieger's anomaly
- Roussy-Lévy Syndrome
- Sagittal synostosis
- Sanfilippo Syndrome (amino acid deficiency)
- Scarring (hypertrophic, contractures, keloids)
- Schaumann's Syndrome
- Sclerocornea
- Scoliosis
- Seizures/epilepsy (convulsive, grand mal, petit mal, absence)  
**Note: febrile seizures are not medically eligible**
- Sequella of rheumatic fever
- Sensori-neural hearing loss
- Short gut Syndrome
- Shorting of limb
- Sick Sinus Syndrome
- Sickle cell anemia
- Silver-Russell Syndrome
- Slipped epiphysis
- Spina bifida
- Spinocerebellar disease
- Spondylolisthesis
- Still's disease
- Strabismus \*
- Sturge-Weber Syndrome
- Subarachnoid or subdural hemorrhage (limited to residuals)
- Subluxation
- Supernumary digits

- Supraventricular tachycardia
- Symblepharon
- Syndactyly
- Systemic lupus erythematosus
- Tachycardia, atrial or ventral
- Tetralogy of Fallot
- Transposition of great vessels
- Treacher-Collin's Syndrome
- Truncus arteriosus
- Tenosynovitis
- Thromocytopenia purpura
- Thyroid disease, hypo-/hyper-
- Tibial Torsion
- Torticollis
- Tourette's syndrome
- Transverse myelitis
- Trigonocephaly
- Trisomy (13, 17, 18(E), 21)
- Tuberous sclerosis
- Turner's Syndrome
- Tympanosclerosis
- Undescended testis
- Vaginal agenesis
- Valvular defects (congenital or acquired)
- Valvular regurgitation/stenosis post rheumatic fever
- Vascular hemangioma
- VATER
- Ventricular defects: hypertrophy, septal (VSD)
- Vesico-ureteral reflux
- Von Willebrand's Disease
- Werdnig-Hoffman disease
- Whipple's Disease
- Williams Syndrome

\*\* Condition subject to eligibility determination by specialty consultant

\* Limitation(s) of treatment duration and/or procedure



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